

Report on the 2013 European patient organisation survey

The European Lung Foundation (ELF) was founded by the European Respiratory Society (ERS) in 2000 with the aim of bringing together patients, the public and respiratory professionals to positively influence lung health.

In 2011, the European Lung Foundation (ELF) sent out a survey to respiratory patient organisations across Europe, asking which lung diseases they represent and what activities they are engaged in. In 2013 we conducted another survey to update the information collected in 2011 and to give a complete picture of the patient organisations in Europe. We have analysed the results of the 2013 survey and compared them with the 2011 survey to produce this report.

Overview

	2011	2013	Total
Number of organisations contacted	237 (across 33 countries)	348 (across 35 countries)	348
Number of surveys completed	82 (across 26 countries)	112 (across 30 countries)	153
Organisation type	1 European, 81 national	8 European, 108 national	8 European, 145 national
Response rate %	34.6	44.3	44.0

In 2013 ELF were able to successfully increase the response to the online survey with a greater number of European countries represented. Interestingly, of the full list of 2011 survey respondents invited to complete the 2013 updated survey, 41 (17.3%) completed the survey again.

5. Which respiratory diseases do you focus on?

COPD	36.61%
Asthma	35.71%
Cystic fibrosis	32.14%
Other	31.25%
Sleep breathing disorders	22.32%
Bronchiectasis	18.75%
Paediatric respiratory disease	18.75%
Lung cancer	18.75%

Interstitial lung disease	17.90%
Rare and orphan lung disease	17.86%
Acute lower respiratory infections	16.07%
Tuberculosis	15.18%
Pulmonary vascular disease	15.18%
Occupational lung disease	12.50%
Acute respiratory failure	10.71%

Other diseases specified

- Alpha-1 Antitrypsin Deficiency
- Idiopathic Pulmonary Fibrosis (IPF)
- Pulmonary Hypertension (PAH)
- Obliterative Bronchiolitis (OB)
- Primary Ciliary Dyskinesia (PCD)
- Mesothelioma
- Histiocytosis
- Allergy

Comparison with 2011 survey

The organisations that completed the 2011 survey represented a similar range of diseases to those completing the 2013 survey. In both surveys, the rarer diseases were less well represented suggesting that the more prevalent lung diseases continue to receive more support both at the national and European level. In 2011 the greatest response was from asthma and allergy organisations (50.7%), followed by COPD (38.8%) and CF (34.3%), which is the same top three for the 2013 survey, although of the organisations that responded COPD was the most frequently represented lung disease.

6. What activities is your organisation involved in?

Providing information for patients	96.43%
Providing advice for patients	84.82%
Raising public awareness of respiratory diseases	80.36%
Communicating with patients via social media	79.46%
Lobbying health departments or governments	72.32%
Working with the media	71.43%

Helping patients communicate with other patients via forums and support groups	68.75%
Communicating research and health policy to the public	65.18%
Offering a helpline service for patients	56.25%
Giving funding for research	46.43%
Recruiting patients for clinical trials	23.21%
Other, please explain	22.32%

Other activities specified

Of the respondents, 22% stated that the organisation is involved in. These fit into the following categories:

- **Prevention/early intervention** – disease awareness, early signs and symptoms, and risk factor (e.g. tobacco) information, campaigns and group sessions; promote adherence to treatment
- **Support** – information, psychological and social support to patients; financial support/donations to patients; legal advice; supporting similar organisations in other EU countries; smoking-cessation workshops
- **Education** – student internships and study guidance, training for healthcare professionals, education for patients on using equipment and self-management; supporting research and working with specialists to provide accurate information to patients
- **Development** – helping develop disease-specific policy and programmes

Comparison with 2011 survey

In 2011 the top four activities performed by patient organisations were: providing information for patients (96.3%); offering advice and support to patients (92.7%); raising public awareness of respiratory diseases (86.6%); and working with the media (76.8%). Although these core functions have remained the same there has been an increase in patient organisation involvement in research activities, ranging from recruiting patients for clinical trials to funding research and communicating policy and research to the public. This may be due to the on-going shift towards patient involvement in healthcare decision-making and condition self-management. It is also important to note the number of organisations using social media to communicate with patients (79.46%). This shows patient organisations using modern technologies to meet the needs of patients, to raise the national and European profile of their organisation and making efforts to communicate with isolated or less out-going patients.

7. Would you be interested in working with ELF and ERS?

Encouraging patients in your country to complete surveys to help us learn more about patient experiences across Europe	61.61%
Taking part in public health campaigns	62.50%

Attending ERS Congress to promote your organisation	52.68%
Helping review and produce patient information on lung health and disease	50.89%
Setting research priorities from the patient perspective	49.11%
Reviewing questions for research surveys	41.96%
Reviewing research proposals for patient involvement	41.96%
Joining ELF Patient Advisory Committee to represent patients at a European level	41.96%
Translating patient information on lung health and disease into your language	40.18%
Finding patients to speak at ERS events (in English)	37.50%
Translating surveys into your language to enable the views of patients in your country to be heard	36.61%
Other	13.39%

Suggestions of other ways patient organisations could work with ELF/ERS

- By staying informed about the work of ELF/ERS
- Student internships and study guidance
- Working with focus groups comprising of patient organisations and their patient members
- Work together through existing European organisations e.g. CF Europe, Alpha Europe Federation

Restrictions to working together

Although no questions were asked about barriers to working together, several organisations stated that they would like to be more involved with ERS/ELF but certain circumstances make this difficult:

- Lack of time
- High existing workload
- Little money and resources
- Already involved with another European level organisation e.g. EFA, EUPATI or CF Europe
- The organisation's national focus makes it difficult to support a wider European agenda

Comparison with 2011 survey

In both surveys, 100% of the organisations wanted to be involved with ELF/ERS in some way. There was consistency between 2011 and 2013 with the majority of organisations interested in working together to produce and review patient information, get involved in awareness campaigns, and attend the ERS Congress. By 2013, there is also greater interest in setting research priorities and reviewing proposals (41.9%-49.1).

In the 2013 survey a greater range of engagement options were provided, with respondents indicating their willingness to get involved in surveys on lung health and patient experiences across Europe, and in reviewing research proposals and priority setting. This shows that patient organisations are keen to be involved in targeted activities related to specific conditions but may not

be as interested in general activities, or in advocating at the European level, considering national or regional concerns as more of a priority. These themes were present in the statements about restrictions on working with ELF/ERS.

Summary

ELF has been delighted by the response to the survey, and looks forward to learning more about and collaborating with all organisations that responded. The response and results of the survey show that patient organisations want to be connected with other lung health organisations, albeit to varying degrees. We hope that the ELF European patient organisation network will help us all to be more aware of the activities of other organisations and to find ways to work together for the benefit of people with lung diseases throughout Europe.

This report, and details of all organisations that completed the survey, have been published on the ELF website and can be found directly at <http://www.europeanlung.org/en/get-involved/european-patient-network/>. On this page is a link to the survey so that other patient organisations can complete the survey at any time and be included in the network.

If you have any questions about the survey, ELF and ERS, or would like to discuss ways of working together, please email Sarah Masefield, ELF Patient Relations at sarah.masefield@europeanlung.org.