

# Patient organisations and the European Lung Foundation

## Introduction



### Key points

- Patients' organisations have traditionally provided support services and a platform for members to share their experiences. Increasingly, however, they are becoming activist, taking a role in public awareness campaigns and advocacy for more research or better healthcare, and forging international partnerships with like-minded groups.
- By training 'expert patients', organisations are making sure patients have an input into new guidelines and treatment recommendations, and healthcare planning.
- Key challenges for the future include maintaining funding levels – particularly for organisations devoted to rare diseases – addressing health inequalities and improving the health literacy of the public.
- Across Europe, a total of 164 respiratory patient support groups have been identified, representing more than a dozen different disease areas.

In the past decade there have been many influences on the way we deliver healthcare. One of the most important transformations has been the way patients and carers are engaged in decisions about healthcare. The acceptance that patients, particularly those with long-term conditions, are experts in their own disease has been at the heart of these changes. Increasingly this experience and insight is being harnessed in healthcare, policy and research in order to ensure goals that are responsive to the needs of patients, leading to better outcomes and improvements in health and wellbeing. People are being encouraged to get involved in a structured and effective way in order to have an input in the future of their condition.

So what is the role of a patient organisation in this climate? A patient organisation is defined by the European Medicines Agency as 'a not-for-profit organisation which is patient focused, and whereby patients and/or carers represent a majority of members in governing bodies'.

This chapter looks at patient organisations – their roles and how they have evolved, and the impact that they have on healthcare. Examples of these activities will be provided from a network of pan-European and national respiratory patient organisations.

The European Lung Foundation (ELF) was founded by the European Respiratory Society (ERS) in 2000. Its aim is to bring together patients, the public and respiratory professionals to positively influence respiratory health. ELF works to communicate and

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translate the work of the ERS to those outside the respiratory profession. However, more importantly in the context of this chapter, ELF works to ensure that patients and patient organisations have the opportunity to influence respiratory research, guidelines and ultimately care.

In June 2011, ELF carried out a Europe-wide survey to identify respiratory-oriented patient organisations. The initial search was carried out in English, as was the online survey. A total of 164 organisations were identified and 88 (54%) responded to the survey. The results obtained will be considered here in relation to the prevalence of lung disease across Europe.

Finally, this chapter will look to the future to see what challenges patient organisations face and how collaborating with professional organisations and speaking with one voice is vital to the future of lung health. The views and opinions of European respiratory patient organisations have been invited and incorporated.

## *The role of patient organisations*

Patient organisations have traditionally provided a supporting role for patients, but their activities are constantly developing and evolving. Here, the evolution of patient organisations and their activities in three fields is discussed, and specific examples of activities are given from respiratory patient organisations in Europe.

### *1. Supporting and advising*

Historically, the sharing of patients' experiences of their own disease was the key reason for the establishment of patient organisations. One of the first organisations to provide support was Alcoholics Anonymous, which was set up in 1937 in the USA. Such organisations offered secure and supportive environments to share experiences and advice. Decades later, this remains a crucial function of the majority of patient organisations. However, the means by which this support and advice is shared has changed.

Many patient organisations still provide face-to-face opportunities to meet and discuss. An example of this is the British Lung Foundation (BLF) Breathe Easy groups, which have been set up in various regions of the UK ([www.lunguk.org/supporting-you/breathe-easy/breathesasygroupsacrosstheuk](http://www.lunguk.org/supporting-you/breathe-easy/breathesasygroupsacrosstheuk)). However, much interaction now takes place online,

## EU-funded initiatives

### PatientPartner ([www.patientpartner-europe.eu](http://www.patientpartner-europe.eu))

The aim of this project was to identify patients' needs for partnership in the context of clinical trials. Moreover, the project led to a well-organised and sustainable communication platform and guidelines, to enable mutually beneficial interactions between patients and clinical trial professionals.

### VALUE+ ([www.eu-patient.eu/Initatives-Policy/Projects/ValuePlus](http://www.eu-patient.eu/Initatives-Policy/Projects/ValuePlus))

The objective of the VALUE+ project was to exchange information, experiences and good practice regarding the meaningful involvement of patients and patient organisations in European Union-supported health projects at European and national level.

through blogs, internet forums and websites. An example is the Pulmonary Hypertension Association (PHA) Europe web tool 'Time Matters' ([www.phtimematters.org](http://www.phtimematters.org)), which aims to give patients a voice. Here, patients and carers can post their hopes for the short-, medium- and long-term future and share their fears with others. A number of patient organisations also provide phone services, nursing support and even experts in indoor air quality for their members and the public.

Patient organisations help people to understand their condition(s). Many still provide comprehensive and clear information on paper, but this is being supplemented with websites, videos and social media. The Asthma Society of Ireland provides an asthma checklist describing what people with asthma should expect from a visit to their general practitioner, and has published inhaler technique videos ([www.asthmasociety.ie/inhaler](http://www.asthmasociety.ie/inhaler)). The Lovexair Foundation Spain has produced a documentary about COPD and  $\alpha_1$ -antitrypsin deficiency ([www.lovexair.com/en/page5/page5.html](http://www.lovexair.com/en/page5/page5.html)) to educate people about the conditions.

## 2. Making change happen

Many organisations have developed an advocacy role, and represent the collective identity of their members in the public and political domain. Patient advocacy groups fight for public recognition of their disease through awareness campaigns, the speed and efficiency of which have been revolutionised by using websites, e-mail and social media. The political impact of patient organisations has also grown as they strive for action and change, and increasingly patient organisation representatives are included in official bodies advising on health policy and care decisions.

For World Asthma Day 2011, Asthma UK launched 'Get it off your Chest', an awareness campaign using an online map. Over 1800 people with asthma shared their stories. Asthma UK presented the stories to UK Members of Parliament during a reception, which enabled them to highlight the seriousness of

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asthma. Nationally, many patient organisations work with their governments and health services. In 2008, the French Federation of Associations of Patients with Respiratory Insufficiency or Handicap (FFAAIR) developed a charter for patients who receive care at home. Created by patients and for patients, it outlines the rights and responsibilities of home-care personnel and patients in order to guarantee effective and high-quality care. The French Minister of Health and 24 societies representing care providers have now signed this charter.

### ***3. Providing the patient perspective***

More recently, patient groups have become involved in scientific and therapeutic activism. The concept of the 'expert patient' or the 'expert of experience' has developed. The aim of the expert patient is to input into research and healthcare using his or her unique expertise – as someone who has first-hand experience of a disease. Although this concept is well accepted in many areas, the evidence to show the impact it can have is still evolving. Many patient organisations have developed processes and methodologies to ensure that their members are fully prepared to get involved in areas such as research and clinical trials, and ensure that patients are available to participate wherever needed. Several European Union-funded initiatives have also brought together patient organisations from across Europe to help others engage as experts in their own disease (see EU-funded initiatives).

Patient organisations are also playing an increasingly key role in research funding, facilitating more research and directing where money is spent. The Netherlands Lung Foundation (Long Fonds; [www.longfonds.nl](http://www.longfonds.nl)) started to involve patients in research and in research and health policy in 1997. In 2007, the Long Fonds established a dedicated advisory board, consisting of patients with respiratory diseases. This board helps to develop standards of care, care guidelines and translations of these guidelines into lay language, as well as establishing research priorities, developing criteria to evaluate research from the patient's perspective, implementing research policies, evaluating research proposals in annual grant rounds, and monitoring ongoing research projects.

Public and patient involvement in European projects has become a key requirement when securing funding. A good example in the respiratory arena is a project called 'Unbiased BIOMarkers in PREDiction of respiratory disease outcomes (UBIOPRED)', a project in which ELF is a partner providing the means for public dissemination of information about the project ([www.UBIOPRED.european-lung-foundation.org](http://www.UBIOPRED.european-lung-foundation.org)). Patients working with the Long Fonds and Asthma UK have played a key role in key stages of the UBIOPRED project: in the development and wording of the proposal itself, in the ethics committee and the safety monitoring board and on the content and tone of the website. The patients involved were also able to give their advice to the project as a whole when there were difficulties with the recruitment rate of subjects for the project.

### ***Distribution of activities***

What is clear from the ELF respiratory patient organisation survey is that most patient organisations today carry out a variety of roles. Indeed, the examples given only represent one activity of each of the organisations. Figure 1 shows the response of the surveyed patient organisations to the question of what activities they perform for and on behalf of patients. The data suggest that the majority carry out the traditional core activities of a patient organisation, including support and providing information, but that additional roles are growing and developing.

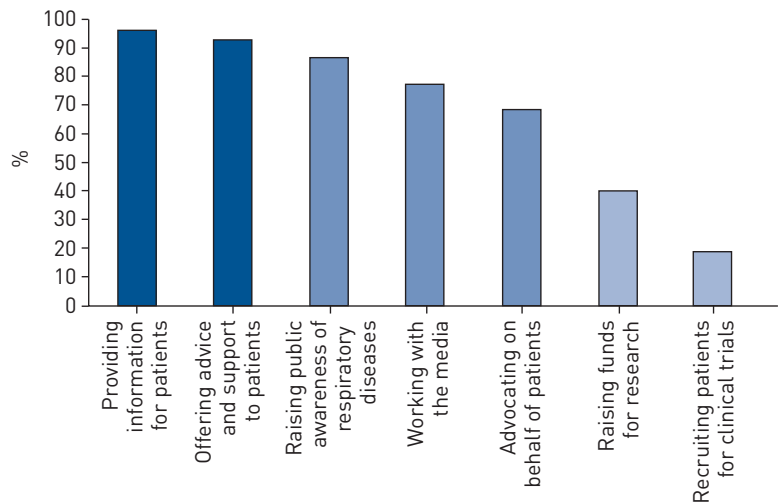
## Pan-European patient organisations

As there is no central registry for patient organisations across Europe or the globe, it is difficult to ascertain how many of them there are. It is clear though that the size and infrastructure of these bodies varies enormously and that the number of voluntary organisations is growing, with more of them representing specific diseases as well as more umbrella organisations across Europe and the world. The increase in the number of pan-European bodies reflects the desire of patient organisations to be part of larger-scale collectives and to be represented at the European level while still maintaining their own identity.

The ELF survey revealed that 87% of national and pan-European respiratory patient organisations are keen to work collaboratively at the European level to raise awareness of lung health, 80% are interested in joining the ELF network of patient organisations, 73% want to be able to participate in the ERS Congress and 52% want to work together to produce patient information. Table 1 lists the pan-European patients organisations that work with ELF.

## Respiratory diseases

Figure 2 shows the number of national and European patient organisations in the respiratory field, and the specific disease areas covered by their activities (more than one could be selected in the survey). Asthma was best represented (by 51% of patient organisations who responded), followed by allergy (42%) and COPD (39%). Some 23 patient groups work with patients with CF. Other diseases listed by respondents include



**Figure 1** – Activities of respiratory patient organisations. The graph shows the proportion of organisations surveyed that carry out a given activity. Source: European Lung Foundation respiratory patient organisation survey.

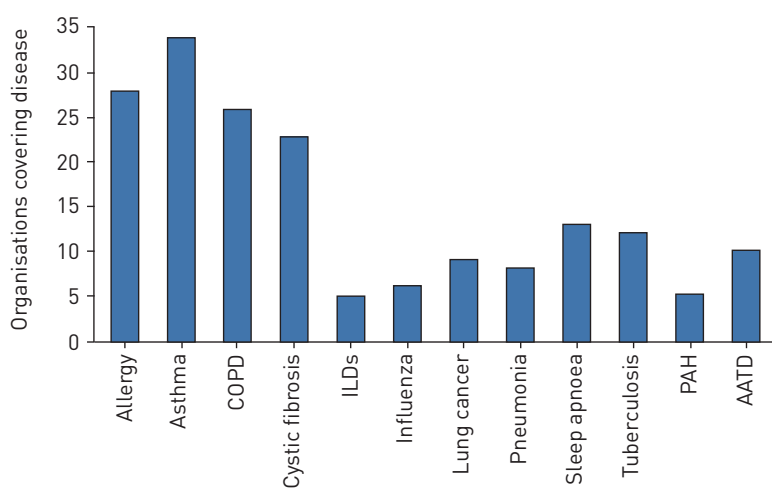
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ELF brings together a network of patient organisations from across Europe  
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Organisation	Description
The European Federation of Asthma and Allergy Patients organisations (EFA)	A network of European allergy, asthma and COPD patients' associations uniting national patient associations at the European level. EFA aims to make Europe a place where people with allergy, asthma and COPD have the right to the best quality of care and a safe living environment and to live uncompromised lives, and are actively involved in decisions influencing their health
CF Europe (CFE)	CFE is the federation of national CF associations in Europe and represents people with CF and their families from 39 European countries. CFE works in close collaboration with other international organisations and is an active partner in several European projects
Pulmonary Hypertension Association (PHA) Europe	The primary objective of PHA Europe is to establish close cooperation between the members of the organisation, European institutions, international organisations and public institutions worldwide
Alfa Europe	Alfa Europe's aim is to provide a European information and resources network for patient support groups and linked associations, health professionals, institutions and industry who wish to improve and extend their knowledge of $\alpha_1$ -antitrypsin deficiency
European LAM Federation	The European Lymphangioliomyomatosis (LAM) Federation focuses on supporting LAM research and coordinates communication with existing LAM patient groups

**Table 1** – Pan-European patient organisations working with the European Lung Foundation. Descriptions are adapted from the organisations' own statements.

sarcoidosis, lymphangioliomyomatosis, mesothelioma, primary ciliary dyskinesia, obliterative bronchiolitis, aspergillosis and rare and orphan lung diseases.

ELF brings together a network of patient organisations from across Europe committed to working together to improve patient care in Europe. This group actively input into the work of the ERS, by being involved in task force and guideline groups, by providing patient speakers at the ERS annual conference and by taking part in EU advocacy work and in public awareness and media campaigns. Pan-European and national patient



**Figure 2** – Disease areas covered by respiratory patient organisations identified by the European Lung Foundation respiratory patient organisation survey. COPD: chronic obstructive pulmonary disease; ILD: interstitial lung disease; PAH: pulmonary arterial hypertension; AATD:  $\alpha_1$ -antitrypsin deficiency.

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groups also actively involve ELF, the ERS and other European and global healthcare professional organisations as partners in their projects and advocacy.

In order to facilitate this interaction, ELF is developing a training programme for patients and their carers, to give them the knowledge and confidence to interact with professionals, policy-makers and the media ([www.EPAPonline.eu](http://www.EPAPonline.eu)). This programme aims to provide information to help patients discover how they can play a role in the development of guidelines, research and policy and also to signpost them to other European resources, such as the European Patients' Academy on Therapeutic Innovation (EUPATI) project, which aims to provide information to patients on medicines research and development ([www.patientsacademy.eu](http://www.patientsacademy.eu)).

## Challenges

Despite their expansion, pan-European and national respiratory organisations face many challenges, which were identified in the 2011 survey as:

- Funding, especially in the current economic climate. Patient organisations are striving to improve their efficiency and to keep costs to a minimum. Many are using strategic planning to focus and prioritise their activities.
- Ensuring that patients' voices are heard in policy and implementation processes both at a national and European level.
- Finding meaningful ways to interact with healthcare professionals.
- Competition between and within patient organisations and professional societies, preventing useful collaboration and hindering progress.
- Rare-disease patient organisations struggling to establish themselves and find the support they need to function effectively.

## The future

As this chapter has highlighted, collaboration is key for successful and productive activities. Equal partnerships between patient organisations and also with professionals and policy-makers must be built and sustained in order to ensure that messages are clear and consistent, and to allow for coordination and better resource use.

Other key priorities for the future of European respiratory patient organisations include:

- Improving the image and standing of patient organisations

in general and ensuring patient groups representing rare or orphan diseases have adequate support.

- Developing innovative methods to ensure an increase in funding, including donations, fundraising, corporate giving and sales. This will also lead to increased support for research.
- Ensuring that patient information and care is based on guidelines and providing it where it is needed most, often at the point of diagnosis or on discharge from hospital.
- Addressing health inequalities and health literacy to ensure that people across Europe are able to obtain the same information and access resources that enable them to better manage their condition.
- Ensuring that patients have more input into research and healthcare at local, national and European level.
- Ensuring that care for chronic respiratory diseases looks to new technologies (e.g. tele-health) and where appropriate alternative treatments.
- All the patient organisations consulted for this chapter have ambitious and impressive plans for the coming 5–10 years. We all look forward to a future where all patients are supported and empowered, and able to contribute to a brighter and better future for themselves and for lung health.

## Further reading



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