



Credit: European Lung Foundation, HLfL event at the European Parliament

Key points

- Although there are many patient organisations in Europe, this is not the case in all countries across the globe.
- Access to care is one of the main global issues highlighted by the European Lung Foundation International Patient Advisory Committee.
- The European Respiratory Society/European Lung Foundation Healthy Lungs for Life campaign can be used locally or globally to raise awareness of the risk factors for lung disease.
- Implementation science is a method that can be used to assess the feasibility of using research findings in routine healthcare in clinical settings in different parts of the world.

Educational aims

To show how patient- and public-focussed initiatives and activities can be adapted and modified to be effective in local, national and international settings, and to provide specific examples of these from the European Lung Foundation.



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European Lung Foundation: from local to global

Introduction

This issue of *Breathe* is focussed on transferring skills, experience and knowledge from the local to the global level. The idea that something which works in a small community or hospital in one town or country can be adapted and amended to have impact in other countries, continents and even across the globe. In this article we will focus on initiatives that have involved the European Lung Foundation (ELF; www.europeanlung.org).

ELF was founded by the European Respiratory Society (ERS) in 2000, with the aim of bringing together patients and the public with respiratory professionals to positively influence lung health. ELF has grown from strength to strength over the last 16 years, growing partnerships with patient organisations and respiratory experts, and integrating patients and patient organisations into the wide range of ERS activities in education, advocacy and respiratory science.

Working with patient groups: ELF patient organisation network

A patient organisation is defined by the European Medicines Agency as “a not-for-profit organisation that is patient focused, and whereby patients and/or carers represent a majority of members in

governing bodies”. There are many different and varied patient organisations at local, national and international levels.

The International Alliance of Patients' Organizations represents 277 patient organisations across 71 countries in 51 disease areas, representing, according to recent figures, 365 million people. This is, however, just a small portion of the total number of patient organisations that exist and do important work to provide support services and a platform for members to share their experiences. Many patient organisations are a key source of research funding *via* their own fundraising activities. In addition, many are involved in public awareness campaigns and advocacy for more research or better healthcare [1].

ELF works with a network of patients and patient organisations from across Europe in the field of lung disease. This is an informal network that can be joined by each respective patient organisation completing a short questionnaire and requesting to be part of the network [2].

In the last year, ELF has focussed on developing links with local and national patient organisations in areas of Europe where it had few or no contacts. This has resulted in 40 organisations joining from 20 countries, including Ukraine, Portugal, Turkey, Belgium, Serbia and Macedonia. Integral to the process has been language support by ELF staff and the use of the new ERS member societies [3] in each country to identify the relevant patient organisations in the field. These new

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Read about ELF's local to global actions in this edition of *Breathe* <http://ow.ly/SQ3d301Py5q>



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organisations were asked to specify areas that were of key importance to them, and responses included the following.

- Maintaining links with European and international organisations.
- Training for patients.
- Connecting with organisations in other countries.
- Fundraising and sponsoring for activities.
- Summer schools and e-learning.
- Developing better internet and social media skills.

At an inaugural event this year, ELF will host a patient organisation networking day on the eve of the ERS International Congress (Saturday September 3) in London to provide networking and training opportunities.

There is much still to be done to develop patient groups across Europe, and to learn best practices in patient involvement. However, in parallel to this more local activity and on the theme of local going global, ELF has been trying to develop links across the world by inviting patient organisations from outside of Europe who attend the ERS International Congresses to attend a meeting of respiratory patient organisations.

The first meeting of this kind, held during the ERS International Congress 2015, in Amsterdam, was attended by organisations from four continents. It was interesting to see how many key topics were felt to be priorities from organisations in diverse parts of the world. A list of those organisations is given in table 1 and the key global issues in figure 1.

ELF is sure that there is a lot of work to be done locally, nationally and globally to harness the voice and views of patient organisations and to combine them with the professional voice to advance respiratory science and healthcare.

Preparing individual patients: European Patient Ambassador Programme

One of the key roles ELF plays is to ensure that patients and the public can have input into scientific and educational activities of the ERS, including being part of a Task Force producing guidelines on the treatment of a particular condition, speaking at the ERS International Congress to ensure that the patient perspective is considered and helping ELF develop patient priorities websites.

ELF developed its European Patient Ambassador Programme (EPAP; www.EPAPonline.eu) in order to make patients ready and able to get involved in determining the future of respiratory healthcare, giving training on how to find reliable information online about science and research, and giving information and advice on advocacy, press and media. EPAP is now being used by 580 individuals in 31 countries, including Serbia, Montenegro, Bosnia and Herzegovina, Macedonia, Ukraine, Morocco, Mexico, Costa Rica, Albania and Latvia. As the patients who take part in the programme are required to be able to interact in English, the programme was first developed in English only.

Although there are many people who have completed the programme and are comfortable in communicating in English and are getting involved at the international level, there are many who wish to use EPAP to be advocates and active patients at a local level. In some of the countries so far represented in the programme, there are one or two ambassadors who have completed the programme in English and are passing what they have learned on to other people in their country who do not speak English. In other countries, where the demand has been greater, ELF is working to translate EPAP so it can also be a national or local resource.

The Netherlands has been at the forefront of the patient-involvement movement, and ELF was approached by the national umbrella organisation for patient organisations (Patiënten en Gehandicapten Organisaties) to work on the translation of EPAP into Dutch so it could be used as a training resource for 200 patient organisations in the country.

Table 1 Organisations who attended the first ELF International Patient Advisory Committee meeting and the country where they are based

Country	Organisation
USA	Allergy and Asthma Network
Global	Alpha 1 Global
Spain	Asociacion Nacional de Hipertension Pulmonar
Ireland	Asthma Society of Ireland
UK	Asthma UK
USA	COPD Foundation
Global	COPD Global
Europe	EFA
Italy	FederASMA e ALLERGIE onlus – Federazione italiana pazienti
France	FFAIR
USA	Foundation for Sarcoidosis Research
Spain	Fundacion Lovexair
Global	Global Allergy and Asthma Patient Platform
Japan	Japan Federation of Patient Organisations for Respiratory Diseases
UK	June Hancock Mesothelioma Research Fund
USA	NTM Info and Research
Austria	Osterreichische Lungenunion
Europe	PHA Europe
USA	Pulmonary Fibrosis Foundation
Brazil	Societal Latin de Hypertension Pulmonary
Brazil	The Brazilian Lymphangioliomyomatosis Association (ALAMDRA)

The Dutch version of EPAP was launched at the ERS International Congress 2015, in Amsterdam, and subsequently, 70 people in the Netherlands have completed the programme; at this stage, primarily those at the head of patient organisations so that they may test it with the view to recommending it to their members. EPAP has already been praised by the national organisation for patients with leukaemia and the national diabetes association in the Netherlands [4].

The Italian version of EPAP is in development and due to be live by the time of the ERS International Congress 2016 in September, with a plan for promotion in coordination with the Italian arm of the European Patients' Academy on Therapeutic Innovation, who are assisting ELF with translation. ELF hopes that, in this way, it can support the work of individual patients locally, nationally and internationally.

Raising awareness: Healthy Lungs for Life

Healthy Lungs for Life (HLfL) is one of the largest lung health campaigns and is organised by ELF together with ERS; raising awareness of the importance of healthy lungs to healthcare professionals, scientists, primary care, patients, policy makers and the public through a range of events, projects and activities. HLfL seeks to reduce the number of people suffering from respiratory disease by raising awareness and knowledge of lung conditions and the ways to prevent lung damage. Each year, HLfL focusses on a key issue that is vital for lung health. These issues include air quality, physical activity, smoking cessation and nutrition.

By incorporating HLfL throughout all ERS and ELF activities, and by utilising the ERS International Congress as the annual driver behind the campaign, together ERS and ELF deliver a loud and clear lung health message. A key feature in the campaign is the city in which the ERS Congress is held each year. It is in this city that the visuals, messages and core activities of the campaign are launched to ERS Congress participants and to the people living there [5].

This year, HLfL will have a strong and hard-hitting impact in London, where the ERS International Congress will be held on September 3–7. ELF and ERS have worked with key UK-based professionals and patient organisations to select a theme for the campaign for 2016 that would be a hot topic in London and the UK and would also have relevance to those in different countries across the world: clean air.

The campaign has secured the iconic Trafalgar Square to host the campaign's signature lung function testing event, which has the potential to gain high media coverage and allow members of the public to learn more about their lung health and how to protect their lungs from pollutants

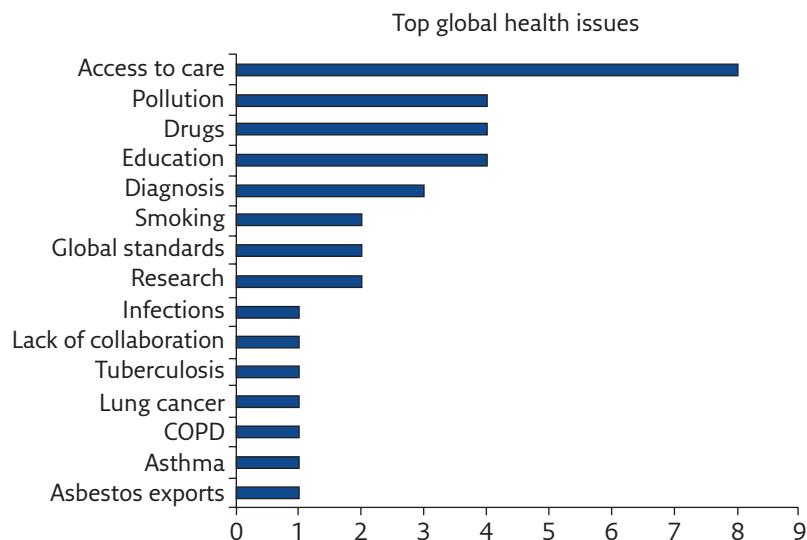


Figure 1 ELF carried out a survey of patient organisations that attended the first meeting of the ELF International Patient Advisory Committee and a number of issues of importance were highlighted.

in the air we breathe. Giant bubbles will be constructed representing “clean air bubbles”.

As well as having the opportunity to use Trafalgar Square as an attention-grabbing act, these clean air bubbles will do a tour of a number of locations across London to ensure that the target audience for HLfL is reached. Sites will include Waltham Forest, Canary Wharf, Camden, Lewisham and Islington.

The ERS International Congress is a big and important event for HLfL and really does provide a springboard and starting point for the HLfL campaign to develop over the year. However, the heart of the campaign aims to support others to hold events and spread the HLfL messages across the globe. HLfL provides toolkits and support for national societies and patient organisations from across the world to hold related events in their own communities at any time throughout the year. Many organisations will use national awareness days to hold an HLfL event and disseminate the HLfL messages.

Here are just a couple of examples of events organised by healthcare professionals and patient organisations under the HLfL banner using the toolkits and materials that ELF and ERS have produced.

Europe

In Athens, Greece, ERS Vice President, Dr Mina Gaga, and members of the Hellenic Thoracic Society organised an HLfL event at the Athens Authentic Marathon in November 2015. As well as having many runners in HLfL shirts taking part in the marathon, Dr Gaga and colleagues also had a stall where people could undergo ergospirometry and talk about lung health. Dr Gaga commented: “The event went very well: it was a huge celebration of

the ability to play sports and be active, and taking control of your life.”

Africa

In September 2015, HLfL funded a spirometry training event for healthcare professionals in Kenya. The training took place alongside the Pan African Thoracic Society (PATS) Congress, which was held in Nairobi, Kenya, on April 9–12, 2016. The workshop was run by Prof Refiloe Masekela and was very successful, with 32 healthcare professionals trained in how to perform lung function testing. Now trained, the participants are enthusiastic about using spirometry with their patients and in their research, and to hold local HLfL events in their communities.

ELF and ERS financially supported the event using donations from delegates and money raised by industry on their exhibition stand during the ERS International Congress in Amsterdam 2015. In addition, spirometry testing equipment was kindly provided by ndd and Pharmaxis.

Lindsay van der Linden, who is part of the ERS Spirometry Driving Licence team and is based in Africa said of the event: “I am very excited about what this will mean in assisting promoting lung health and the use of spirometry on this side of the world.”

Collaborating on European Union projects: FRESH AIR global action for healthy lungs

FRESH AIR (Free Respiratory Evaluation and Smoke-exposure reduction by primary Health Care Integrated Groups) is a 3-year European Union Horizon 2020-funded implementation

science project, to improve prevention, diagnosis and treatment of chronic lung diseases where resources are limited.

Around 90% of deaths from chronic obstructive pulmonary disease and 80% of deaths from asthma occur in low- and middle-income countries (LMICs) [6]. Over the next 3 years, FRESH AIR will explore why so many people in LMICs are dying from chronic lung diseases and what can be done to reduce the burden. A set of implementation science studies will examine the burden of chronic lung diseases, their risk factors, public awareness of these risk factors and how evidence-based approaches to prevention, diagnosis and treatment can be implemented in affordable and appropriate ways. The project will achieve this through seven specific objectives, which are shown in table 2.

The aim of the project is to take well-published findings and interventions that have been researched and used in high-income countries, and test how to adapt them for use in countries with fewer resources in terms of trained staff, public knowledge, equipment, medicines and money, so that they are sustainable, impactful and equitable. The countries involved are Uganda, Kyrgyzstan, Vietnam and rural Greece.

The project shows an example of local to global in two ways. First, the project itself is an extension of previous work funded by the International Primary Care Respiratory Group (IPCRG). Second, it will use interventions, such as pulmonary rehabilitation, which now has a strong evidence base for its use for patients with chronic pulmonary disease, and see how this can be used in countries with completely different healthcare systems, community structures and beliefs:

“We are mapping out the impact of tobacco and indoor biomass smoke on people’s lung health in detail, but more importantly testing with local people how best to adapt

Table 2 Key objectives of the FRESH AIR campaign

To identify the specific factors that influence the implementation of evidence-based interventions in the prevention and treatment of non-communicable lung diseases in community settings
To explore which awareness-raising approaches are most effective in motivating behaviour change in tobacco consumption and personal exposure to air pollution
To provide access to smoking cessation support by adapting successful evidence-based Very Brief Advice (VBA)
To test the feasibility and acceptability of methods for diagnosing COPD using innovative spirometry
To test the feasibility and acceptability of pulmonary rehabilitation (PR) as a low cost treatment for obstructive lung disease
To test how to best reduce children’s respiratory symptoms and the risk of lung damage by exploring the feasibility, acceptability and optimal organisation of interventions
To generate new knowledge, innovation and scalable models that ensure equitable access and to support their implementation through proactive engagement and dissemination

See www.theipcr.org/freshair/work-packages/wp-5-improving-diagnosis-and-treatment for more about the interventions.

existing solutions to their needs and context.”
Siân Williams, Executive Officer of the IPCRG.

In many of the communities it is so normal to have symptoms such as cough or breathlessness that few people report them to the health services, or make the connection between the smoke they breathe and how they feel. Prof Talant Sooronbaev from Kyrgyzstan says “My people often just say they are tired.” So the project aims to describe the problem so that local people, healthcare professionals and governments agree there is a problem and work together to find solutions.

One of the ultimate aims of any indoor air pollution project should be to help local people find ways to use clean, sustainable fuels, but that is not yet feasible in most low resource settings. Therefore, there are a number of projects run by a range of organisations that have introduced stoves that issue less smoke. In the past, these have been primarily to reduce the amount of fuel needed but now more are designed with improved lung health in mind. Research has shown that those solutions can differ for each country, so it is important to ask the population to contribute ideas and to give them a greater say in the matter.

A project being implemented in the slums of Bangalore, India, has uncovered valuable feedback that the clean cooking stoves available are not necessarily suitable as they cook the food too fast and don't fit the large cooking pots used by the families. In Ethiopia, another project failed because the fuel used by the very efficient cooking stoves was too expensive; as a result, all the stoves ended up as scrap on the black market.

The original IPCRG projects encountered similar experiences. In Vietnam, it was recommended that people build chimneys in their homes, something that had been done very successfully in China. In the end, however, it turned out that people didn't want the chimneys because they believed ghosts would use them to enter the house; cooking under canopies outside the house turned out to be a much more viable solution.

In the highlands of Kyrgyzstan stoves are also used to heat the yurts that have to be kept closed for 8 months of the year due to the cold. The highlanders live at about the treeline and therefore use animal dung as fuel, which creates a permanently smoky atmosphere.

The researchers hope to develop a checklist with the local communities, in which a number of variables, such as local cooking habits, cultural practices and the available fuel, determine which solution is the most suitable for them.

Pulmonary rehabilitation is another prime example of an intervention with strong evidence of success in improving lung health and people's quality of life that is not available in many parts of the world. The FRESH AIR project is testing its

Self-evaluation questions

- How many patient organisations are registered with the International Association of Patient Organisations?
 - 277
 - 567
 - 2908
 - 98
- What was perceived as the issue of most importance from organisations that were part of the ELF International Patient Advisory Committee meeting in Amsterdam 2015?
 - Access to care
 - Environment and climate change
 - Smoking
 - Education
- Which language has EPAP already been translated into currently?
 - French
 - German
 - Polish
 - Dutch
- What is implementation science?
 - Implementation science is a method to promote the uptake of research findings into routine healthcare in clinical, organisational or policy contexts.
 - Implementation science is a method to assess how well a scientific procedure is used in a laboratory setting.
 - Implementation science is the study of kitchen utensils.
 - Implementation science is a means by which healthcare professionals can assess whether a healthcare policy is being introduced successfully.

feasibility in low resource settings. In Uganda, for example, there are two main differences to its use in high-income settings. Here people with obstructive lung disease do not have access to any inhaled medicines. So, FRESH AIR can see if pulmonary rehabilitation alone can make a difference to their lives. Also, where there is no government safety net, FRESH AIR can count the benefits to individuals who have completed pulmonary rehabilitation in terms of their economic productivity and ability to participate fully in their village life: caring for grandchildren, going to school or taking a job. ELF has a role here to produce educational materials that are adequate for each setting and adapted to the communities that are being targeted; taking its materials from a local level to a global level. To receive updates on emerging results from FRESH AIR, sign up at www.theipcr.org/freshair/newsletter

Conclusion

ELF is a European organisation focussed on working with patients and patient groups across

Suggested answers

1. a.
2. a.
3. d.
4. a.

the continent. Europe is the focal point; but, as presented in this article, ELF has actions at very local and distinctly global levels. As ELF moves forward, we hope to develop our global links

and activities in line with the ERS membership strategy, and to ensure that respiratory patients worldwide can have a voice and improve their care and the care of others in the future.

Conflict of interest

P. Powell is an employee of the European Respiratory Society. Other disclosures can be found alongside this article at breathe.ersjournals.com

References

1. Patient organisations and the European Lung Foundation. *In: European Lung White Book*. Sheffield, UK, 2013. www.erswhitebook.org/chapters/patient-organisations-and-the-european-lung-foundation/
2. Available from www.europeanlung.org/en/get-involved/european-patient-organisation-network/
3. Migliori GB, *et al*. The European Respiratory Society plans its future: the 2013–2018 strategic plan. *Eur Respir J* 2014; 43: 927–932.
4. Available from http://pgosupport.nl/page/Nieuws-1/Online-cursus-ondersteunt-patientvertegenwoordigers-met-nuttige-kennis?mod%5bPGO_NewsModule%5d%5bn%5d=908
5. Eickelberg O, Fletcher M, Barnes P. Healthy Lungs for Life campaign: a festival of lung health for the ERS International Congress, Munich and the globe. *Breathe* 2014; 10: 5–7.
6. World Health Organisation. Global status report on noncommunicable diseases. Geneva, 2010. Available from www.who.int/nmh/publications/ncd_report_full_en.pdf