



Credit: European Lung Foundation

Educational aims

- To understand the importance of educated patients (patients that are knowledgeable on their condition and how healthcare processes work).
- To understand the importance of guiding patients to quality reliable sources of information and education.
- To establish ways to ensure that healthcare professionals are prepared to work with educated patients.
- To outline the initiatives that ELF has driven forward in the field of education.
- To see the value in patients advocating at the European level for raising standards of education for patients and physicians.



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What do patients know? Education from the European Lung Foundation perspective

The European Lung Foundation (ELF) is an organisation whose mission is to bring together the public and patients with respiratory professionals to improve lung health. A core part of all its activities focus on education: the education of patients on their condition, including how to prevent, treat and manage it; the education of healthcare professionals on how to improve work with patients and awareness about the issues that are important to patients; and education of the public and policy makers of the importance of lung health at a European level. ELF was founded and works in a unique partnership with the European Respiratory Society (ERS).

This article has been written by the recent past Chairs and the new Chairs of three ELF committees (Council (D. Smyth and I. Saraiva), Professional Advisory Committee (K. Lisspers and G. Hardavella) and Patient Advisory Committee (J. Fuertes and K. Hill)) in order to reflect on ELF's journey in this regard over recent years. In particular, it seems a good moment to assess the success and impact of the first patient Chair of ELF, Dan Smyth, and reflect on what this has meant for ELF's educational activities, and what the future now looks like.

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Is an educated patient a better patient?

Times are changing. Public expectations are rising in all aspects of life, people expect quick and effective service whether it is in a shop, on the phone, online or in their doctor's surgery. The change began with mass education in the early 1900s, then the introduction of mass media and now the internet revolution. People are informed, have knowledge to hand and they are using it in all aspects of their life. With respect to healthcare, this change to a consumer society means that doctor–patient

relationships are changing. The number of patients who visit their doctor today without having already done their own research is falling. The number of patients who will accept advice from their healthcare provider without discussion or questioning is in decline.

An informed public, able to look after their own health and prevent disease, is a good thing. An empowered patient able to manage their own long-term condition and treatment is a positive. However, this cannot be a reality unless both sides are adequately educated. For patients, this means ensuring that they are receiving the right information, at the right time and from the right



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A quick look at the importance of educating patients and healthcare professionals to strengthen the patient–professional partnership from the European Lung Foundation perspective <http://ow.ly/EZbg30hV01Q>



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sources. Moreover, they need to understand it in order to take informed decisions. For the healthcare provider, education is needed to change their role from director to guide, to shift the balance of decision making from the doctor to a collaborative approach that will promote patient-centred care. Patients' goals, personal preferences, cultural beliefs and lifestyle will be considered to ensure an individualised approach to patients.

ELF and ERS are uniquely placed to address education on both sides of this issue. The evolution of ELF, and how it works with ERS, demonstrates that developments in this area can happen and result in positive outcomes for all. ELF is able to ensure that all the materials and educational resources it produces are based on scientific and clinical excellence. Every educational offering is co-produced with patients and professionals, ensuring the right questions are asked and the right answers are provided.

ELF saw its first patient Chair appointed in September 2014. As a sleep apnoea patient, Dan Smyth had the daunting task of chairing the ELF Council, and sitting on the ERS Executive Committee and Management Group. Patients are now involved in almost all ERS Task Forces and guidelines, and the first patient co-Chair was appointed this year to an ERS Clinical Research Collaboration.

Times have changed in ERS, and the unique professional-patient educational partnership that ERS and ELF offer is helping to improve the future for lung patients in Europe, and across the globe.

How have we educated?

A number of the education initiatives that ELF has been involved with are highlighted here.

Educational materials

ELF has 43 factsheets available on its website in 27 languages (www.europeanlung.org/en/lung-disease-and-information/factsheets). These materials serve as a key tool for ERS members to ensure that the information they refer their patients to is reliable and up to date. In addition, healthcare professionals can be assured that the information in all languages is of the same quality, so they can refer a patient whose first language may not be the same as theirs with confidence. In addition, the topics covered by ELF in these factsheets are now in alignment with ERS Task Forces and guidelines. ELF ensures that all recommendations from ERS are translated into a lay format so that they can be shared with patients.

Making the ERS International Congress accessible to patient organisations

ELF has worked hard over the past few years to improve accessibility of the ERS Congress to patient

organisations. It is vital that patient organisations are able to access the latest findings at the Congress to enable them to keep their members up to date. ELF supports a number of patient organisations to attend the conference and be part of the World Village. This provides a dedicated space for national respiratory societies and patient organisations to network. ELF also holds a patient organisation day on the first Saturday of the Congress, where the wider ELF patient organisation network can meet, share ideas and learn from each other's experiences. Finally, patients are now included within the main Congress programme as speakers and demonstrators in scientific and educational sessions. Having a patient set the scene, answer questions or give their view of a hot topic provides a rounded educational experience for those attending the conference (<https://erscongress.org/programme-2017/elf-patient-organisation-programme-2017.html>).

Helping people to breathe clean air and take the active option

Healthy Lungs for Life, launched by ERS and ELF in 2014, is one of the first health campaigns to really focus on prevention rather than the identification and treatment of disease (www.healthylungsforlife.org). Following on from the UN High-level Meeting on Noncommunicable Diseases (NCD) in 2011, it is clear that prevention is key in the big four chronic diseases (lung, cardiovascular, diabetes and cancer). Focusing efforts on educating all stakeholders (the public, patients, policy makers and healthcare professionals) about the factors that can prevent these conditions is essential to ensure that the targets for NCDs can be met.

One key part of the campaign in 2016 was establishing a way that healthcare professionals could explain the risk of air pollution to patients. In order to do this, a workshop was convened, where patients posed the questions they wanted answered and the experts debated how best to answer them. Key lessons learnt were that patients wanted to know the risks of air quality compared to those of smoking, and that general practitioners and other healthcare professionals are not being educated on how to have these discussions with their patients. This led to the development of an infographic to enable doctors to have a structured discussion with their patients about the risk of air quality for their condition.

In 2015, the campaign focused on physical activity. ELF was able to influence the tourist board in Amsterdam to add cycle and walking routes with better air quality to its city map, thus educating those in the city that careful selection of a route in the city can lead to a lower exposure to pollution.

Breathing FRESH AIR globally

The International Primary Care Respiratory Group (IPCRG)-led FRESH AIR project has

presented new challenges for the ELF team (www.theipcr.org/display/DoResearch/FRESH+AIR+Horizon+2020+Project). With a focus on indoor air pollution in low- and middle-income countries, the issues facing the regions covered by the project, and how they are manifested, are very different to Europe. These include biomass burning for heating and indoor cooking, and high levels of smoking. For this project, ELF has had to work with partners in those countries and regions (Vietnam, Kyrgyzstan, Uganda and Crete) to ensure that materials are fit for purpose and relevant to the local context and environment. A five-step booklet on what chronic obstructive pulmonary disease (COPD) is and how it is managed has been developed and all ELF materials have been translated in Vietnamese.

Staying well in the workplace

Occupational lung disease is an often neglected area. Many people work in unacceptable conditions, with risks to their lung health that they are not aware of, or feel unable to do anything about. In some cases, where people do experience the negative impacts of their workplace on their lung health, the cause is not identified or there is a delay in diagnosis. If the healthcare professional doesn't ask or the employee doesn't mention it, the symptoms and underlying cause of asthma, COPD or even lung cancer and silicosis, can go unnoticed until it is too late. ELF, together with experts in the field, has developed an online quiz that allows individuals to answer simple questions about their work environment and whether it could be affecting their breathing (<http://yourlungsatwork.europeanlung.org>). Importantly, it follows up by giving educational tips and advice on protecting the lungs in the workplace and encourages individuals to speak to their healthcare provider about their work environment if there are concerns. The tool is currently in English, and ELF hopes to translate it into further languages with in-country partners so that more people are able to access it. This effort will be mirrored at the ERS level, where healthcare professionals will be educated about the risk in the workplace and the questions they should be asking their patients.

Feeling free to travel with oxygen

Many individuals who have a chronic lung condition will end up having to take supplementary oxygen for some or all of the day. This change in circumstances often doesn't take away the need or desire to travel, yet patients regularly face serious issues when arranging air travel. Over the past year, ELF has worked to find out the key issues in this area for patients and healthcare professionals, and has made real efforts to ensure that people who need oxygen when they are travelling by air know what

they need to do and when (www.europeanlung.org/en/lung-disease-and-information/air-travel). ELF also arranged a symposium at the ERS International Congress in Milan to raise the topic with healthcare professionals. Finally, we will be meeting with airports and airlines representatives to find a solution to educate airline staff about the anxieties and needs of lung patients travelling by air.

Becoming an patient ambassador

As more and more patients have started to play a role in developing guidelines, the ERS International Congress and research projects, it has become clear that ELF needs to find a way to support individuals in preparation for these challenges. The language used in these projects may be complicated, the concepts difficult and the issues complex. Although many patients are keen to work in partnership with professionals, policy makers and the media, they may also lack the confidence or belief that they can do it. To address all these needs, ELF has developed the European Patient Ambassador Programme (EPAP), a free online course to educate patients about all the activities that they can become involved with (www.EPAPOnline.eu). The course takes about 15 hours to complete and is now also available in Dutch, French, Italian and German enabling patients to learn and study in their own language.

Course for professionals

To mirror EPAP, ELF worked with the ERS education department to produce an online course for professionals to learn how they can best support patients in getting involved with their initiatives and projects (www.ers-education.org/events/courses/from-research-to-bedside-the-benefits-of-involving-patients-in-respiratory-healthcare.aspx). This course included testimonies and case studies from patients, and ensures that both sides are educated in the same way.

Self-assessment questions

1. How are the educational needs of patients changing?
 - a) Patients are becoming more like consumers – researching their condition and wanting a choice in the treatment they are given
 - b) Patients are now more likely to accept their doctor's advice without discussion and debate
2. How can these changing needs be met?
 - a) By becoming more firm with patients and telling them what they must do
 - b) By ensuring that patients have the materials they need to educate themselves on their disease from reliable resources

What is next?

ELF has just completed a 3-year plan to guide its activities over the coming years. In addition, ERS is in the process of reviewing its strategy for 2018-2023.

Key points to highlight in the ELF 3-year plan include a greater focus on advocacy at the European level, using the patient voice and patient experience to educate policy makers alongside ELF and other European partner patient organisations to ensure that respiratory health is high on the European agenda. The patient community is becoming more and more aware that it can work together while preserving their individual identities, using common themes and campaigns to help support their more specific goals. Patient organisations are becoming more and more professionalised, but it is still very common to find associations with very small teams. A solid base in advocacy will give access to larger organisations and enable smaller teams to exert their influence in a more efficient way.

Better use of social media and digital communications will also be increasingly important, in order to reach more people where they are having conversations about their lung health and concerns. We will work with ERS to ensure that the information at the ERS International Congress is communicated even further by working with national patient groups to translate and highlight the key issues each year. Although the consumer revolution has allowed individuals more freedom and choice, it has also exacerbated inequalities and the socioeconomic divide. ELF must strive to ensure that those who really need information and education can access it, to support them in becoming better managers of their own health.

We will also be working alongside the European Reference Networks (ERNs), specifically with ERN-LUNG, which focuses on rare lung conditions, to increase awareness and understanding of rare respiratory conditions that affect a limited number

of individuals but can have a devastating impact on their lives. The ERN structure requires involvement and engagement of patients at every level of the network. More empowered and expert patients are needed to occupy their place within the ERNs and education of patient representatives is a key element in making ERNs a success.

The new ELF strategic plan will also focus on educating ERS members in patient and public involvement (PPI), with the aim to improve and facilitate their awareness and understanding of PPI, as well as systematic involvement by developing appropriate training activities. To facilitate this we will plan relevant training opportunities within the ERS and will expand them on a national level by promoting external networking and partnership working with national respiratory societies and national patient organisations across Europe. The second phase of increasing awareness will target educating undergraduates in collaboration with universities and colleges across Europe. Our aspiration is to embed PPI training in undergraduate education and invest in increasing awareness and knowledge among tomorrow's professionals.

To support these activities, we will use our wealth of expertise and develop clear guidance, centralised resources and tools for all professionals working in respiratory research and care to be able to engage patients in their activities, including guideline production, clinical research collaborations, research and service development. We will establish and improve processes to monitor, evaluate and review the impact of ELF activities and interventions in patient and public awareness and be guided by outcomes as well as ERS/ELF strategy for future projects.

Finally, this year, the ERS Presidential Summit will focus on the needs of patients for the first time. Prior to this, healthcare professionals, patient organisations and patients will be asked what they think the major trends and challenges will be in the field of lung health in the next 5 to 10 years. These views and opinions will be presented at the summit. A multi-stakeholder panel and audience will then try to establish action plans and priorities for addressing the issues identified. We firmly believe that education will play a central role in any solution.

Summary

The overarching aim of ELF is to improve the lives of people living with lung conditions and to prevent people from developing these conditions in the first place. Care should be patient-centred and we should ensure that patients are empowered to take on responsibility for their own care. Furthermore we should support patients to become advocates for care quality, regardless of where they are located, and to contribute to raising standards of

Educational resources

- ELF factsheets: www.europeanlung.org/en/lung-disease-and-information/factsheets
- Healthy Lungs for Life: www.healthylungsforlife.org
- ELF occupational health quiz "Is your workplace affecting your breathing?": <http://yourlungsatwork.europeanlung.org>
- Air travel with supplementary oxygen: www.europeanlung.org/en/lung-disease-and-information/air-travel
- European Patient Ambassador Programme: www.EPAPOnline.eu
- From research to bedside: the benefits of involving patients in respiratory healthcare (course for professionals): www.ers-education.org/events/courses/from-research-to-bedside-the-benefits-of-involving-patients-in-respiratory-healthcare.aspx

care through meaningful cooperation with their physicians. Education is key to achieving our goal and we must be innovative, forward-thinking and inclusive to maximise its leverage.

Conflict of interest

P. Powell is an employee of the European Lung Foundation. D. Smyth has nothing to disclose. I. Saraiva has nothing to disclose. K. Lisspers reports personal fees (for educational activities and lectures) from Novartis, AstraZeneca, and TEVA; and personal fees (for scientific steering committees) from Novartis, and AstraZeneca; all outside the submitted work. G. Hardavella has nothing to disclose. J. Fuertes has nothing to disclose. K. Hill has nothing to disclose.

Suggested reading

1. Neuberger J. The educated patient: new challenges for the medical profession (Review). *J Intern Med* 2000; 247: 6–10.
2. Coulter A, Entwistle V, Gilbert D. *Informing Patients: an Assessment of the Quality of Patient Information Materials*. London, King's Fund, 1998.
3. Snow R, Humphrey C, Sandall J. What happens when patients know more than their doctors? Experiences of health interactions after diabetes patient education: a qualitative patient-led study. *BMJ Open* 2013;3:e003583.
4. The patient voice. Pan European Networks, November 2014; pp. 121–123. www.paneuropeannetworkspublications.com/ST13/files/assets/basic-html/index.html#121
5. BMJ Blog. Dan Smyth: Patient involvement in the European Respiratory Society Congress 2015–16. <http://blogs.bmj.com/bmj/2016/09/14/patient-involvement-in-the-european-respiratory-society-congress/> Date last updated: Sept 14, 2016.
6. BMJ Blog. Dan Smyth: The European Lung Foundation's patient organisation day. <http://blogs.bmj.com/bmj/2016/11/11/the-european-lung-foundations-patient-organisation-day/> Date last updated: November 11, 2016.

Suggested answers

1. a.
2. b.