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## Editorial

# Where are the gaps in education in the field of rare lung disease? Perspectives from the ERN-LUNG educational programme survey

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Rare diseases affect fewer than one person in 2000 in Europe. There are >6000 that have been identified, with the majority (80%) being genetic in origin [1]. Due to the small number of people living with these conditions, they are often neglected; diagnosis is difficult and treatment options limited. European reference networks (ERNs) are a new European Union (EU) initiative that aims to ensure that people living with rare conditions can benefit from the best treatment and advice wherever they live in the EU (<https://ern-lung.eu/>).

ERN-LUNG is the respiratory focused ERN, the vision of which is to be a European knowledge hub for rare and complex lung diseases, and to decrease morbidity and mortality in people of all ages. This ERN covers nine disease areas, including interstitial lung diseases, cystic fibrosis, pulmonary hypertension, primary ciliary dyskinesia, non-cystic fibrosis bronchiectasis,  $\alpha_1$ -antitrypsin deficiency, mesothelioma, chronic lung allograft dysfunction and other rare lung diseases.

As well as these core disease areas, ERN-LUNG has nine functional committees: research and clinical trials, ethical issues, registries and biobanks, patient-recorded outcomes, quality management, guidelines and best practice of care, communication and outreach, cross-border care, and training and education. The aim of the education committee is to ensure that professionals and patients can access up-to-date and relevant educational materials to help diagnose, treat and manage rare lung conditions.

The education committee felt that a good starting point for the work of the group was to carry out a survey among ERN members (healthcare professionals working in national reference centres) and patients (from the European Lung Foundation (ELF) patient organisation network) to find out the current situation in Europe.

## The survey

A total of 52 healthcare professionals (out of 60 invited) and 57 patient representatives responded to the survey, which was composed of seven questions for healthcare professionals and five for patients, and was posted on SurveyMonkey in English for 3 months.

## The view of healthcare professionals

>75% of healthcare professionals are aware of educational resources in the field of rare lung diseases and 95% believe that those resources are relevant for delivering the educational mission of ERN-LUNG. A comprehensive list has been put together based on the resources suggested by survey respondents (available at <https://ern-lung.eu/>).

There was a consensus that education is mandatory but none on the form that educational



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**It is vital that education in the field of rare lung rare disease is made a priority for healthcare givers as well as for patients** <http://ow.ly/ysPs30o9v6b>

resources should take, and a variety were supported including postgraduate courses, online courses and webinars, case-based sessions, and expert forums.

The survey respondents were asked to give a preference on who should develop educational resources in the field of rare lung diseases, and the majority (>75%) suggested that materials should be developed in partnership with organisations such as the European Respiratory Society (ERS), and integrated into existing meetings and events run by such organisations.

## The view of patients

From a patient's perspective, 88.5% of respondents thought there was a need for patient education at a European level. However, only 34.8% were aware of such activities. Several resources were indicated, which are also available at <https://ern-lung.eu/>. Patients reported a number of barriers that prevent them from accessing education; these include language, cost of travel, and bad health limiting how and when they can travel. Due to these limitations, 67.5% and 82.5% of respondents indicated that online meetings and online resources, respectively, would be the preferred route of delivering educational resources, although 60% still suggested that face-to-face meetings would be welcomed. Finally, an overwhelming majority (95%) of patients

who responded thought that patients had a role to play in the education of professionals.

## Conclusions

It is vital that education in the field of rare lung disease is made a priority within and outside of the ERN-LUNG and for healthcare givers as well as for patients. The conclusions taken from the survey are as follows.

- A dynamic overview of resources should be made available on the ERN-LUNG website that can be regularly updated.
- Education should be performed in conjunction with medical societies (*e.g.* ERS) and patient-focused organisations (*e.g.* ELF).
- There should be a conscious effort to make patient educational materials more accessible by translation and improving online functionality.
- There is an urgent need for funding to structurally improve education and access to education for all healthcare professionals and patients in Europe in the field of rare lung disease.

These conclusions will be taken forward by the education committee of ERN-LUNG and we invite all those working in the field to get involved.

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### Conflict of interest

P. Powell is an employee of the European Lung Foundation. M. Kreuter reports grants and personal fees from Boehringer Ingelheim and Roche outside the submitted work. M. Wijsenbeek-Lourens has nothing to disclose.

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### Reference

1. Gibson GJ, Loddenkemper R, Sibille Y, *et al.*, eds. The European Lung White Book. 2nd Edn. Sheffield, European Respiratory Society, 2013.