ERN-LUNG - Added Value of Patient Involvement in the development of ERN Clinical Guidelines

About ERN-LUNG & Rare Lung Diseases

- ERN-LUNG aims to cover all rare respiratory diseases and improve clinical care for patients.
- Rare respiratory diseases are complex and can have significant impact on the heart, circulation, brain and metabolic function due to impairment of ventilation and gas exchange. These diseases significantly impact on quality of life and prognosis for patients and require specialist multidisciplinary care. Early diagnosis is associated with improved prognosis, however, delay in diagnosis remains a challenge and can take years or decades.
- The network has nine core networks:

Interstitial lung disease	Non-CF bronchiectasis	Pulmonary hypertension
Cystic fibrosis	Alpha1-antitrypsin deficiency	Mesothelioma
Primary ciliary dyskinesia	Chronic lung allograft dysfunction	Other rare Lung diseases

Purpose

- Patient involvement is generally perceived as beneficial and recommended in developing clinical guidelines, however there is no clear consensus to the most effective approaches. There is a need to understand the value this can bring and obtain the optimal approaches to involving patients in the development of clinical guidelines, whilst understanding the need to be flexible depending on the issues being covered.
- The opportunity to draw on both the published evidence and the experience of clinicians and patients to form consensus where there are gaps in evidence is critical to improving diagnosis, care and treatment for rare and complex diseases and highly specialised healthcare.
- Guidelines are an important tool to enable ERNs to share their knowledge and drive forward improvement.

Model For Participation

Preparation
- Patient Advisory Group with 2 Patient Representatives sitting on Guideline Committee
- Help formulate questions & rate importance. Review of patient experience, unmet needs and gaps
- Identify and rate outcomes used in assessing treatments

Research
- Patient-centred literature review aims to collect the patient experiences that might get missed by the main scientific review
- Where there is gaps in evidence, focus groups and surveys can be performed to fill in any gaps
- Patients to grade evidence with clinicians as they are best placed to balance benefits and harms

Writing
- Integration of patient input in final guideline document.
- Patients review recommendations and provide practice advice for patients in the guidelines and recommendations.

Implementation
- Develop lay version in a 'patient and parent-friendly' format
- Dissemination and communication of guidelines across patient community

Method: The proposed model above draws on patient involvement models from NICE and SIGN and 15 years of experience from European Lung Foundation (ELF) which collaborates closely with the European Respiratory Society (ERS) to involve patients in all their activities

Results

- Patient insights can be invaluable as they are 'experts living with the condition', so provide insights from a different angle to clinicians. They are the best people to say what outcomes are important when making decisions about health!
- Patient input is important at each step in the guideline process and it ensures the final guidelines answer the needs of patients!
- Patients may require support to ensure they understand their role in the process and have the capacity to provide meaningful input.
- Patient involvement in reviewing and grading the evidence and writing the recommendations improve the relevance of the guidelines for patients and improve implementation and use
- Patients developing a patient-targeted version of the guidelines is effective in ensuring patients have access to treatment information

Conclusion

- The experience of ELF and ERS has developed the 'best-practice approach' for involving patients in guideline development and their added value – although flexibility in the process is key.
- Establishing a Patient Advisory Group with two Patient Representatives from this group being formal members of the Guideline Committee optimises the active involvement of patients into guideline development.
- Some patients may be reluctant to input and clinicians can be resistant to receiving their input. A clear proven process and good communication should overcome these barriers.
- Having patient input early can identify patient priorities to ensure they are considered in the objectives of the treatment guidelines, ultimately making the guideline both relevant and usable for clinicians and patients. ERN-LUNG will use this patient for involving patients in guideline development in the network.

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