

Guide for Patients: providing patient perspectives in European Respiratory Society (ERS) projects and activities.

Introduction

The European Lung Foundation (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.

ERS is a professional membership organisation which helps to improve standards of care in respiratory medicine across Europe by producing its own guidelines and documents for healthcare professionals. Its members are individuals working in the field of respiratory health and include respiratory specialists, medical practitioners, scientists, researchers, and allied health professionals, such as nurses and physiotherapists.

ELF provides the patient voice in ERS activities. ERS recognises that patient and public input into clinical practice guidelines, research and education adds value and can increase the relevance and impact of projects.

This guide provides information for patients and carers on what is involved as a patient representative in an ERS project.

ERS projects and activities

ELF works closely with ERS and project Chairs to ensure that patient perspectives and issues are highlighted through the direct input of patients and carers into ERS activities, mainly through Task Forces and Clinical Research Collaborations (CRCs).

What is a Task Force?

A Task Force is a group of healthcare professionals who come together to address a specific issue in respiratory medicine that they feel passionately about and which needs looking into more closely to improve how respiratory professionals' practice.

Any ERS member can apply for funding to set up a Task Force and ELF supports patient representatives to be involved.

Each Task Force will produce a clinical practice guideline, statement, or technical standard to give healthcare professionals guidance on how to diagnose, treat and manage different lung conditions and related issues. These will then be published as official ERS documents. A description of each type of document is below:

- *ERS clinical practice guidelines* – reviews published scientific research on the topic and makes recommendations on how to use the research evidence in everyday practice.
- *ERS statement* – reviews published scientific research on the topic as with a guideline but does not provide recommendations.
- *ERS technical standard* – reviews published scientific research to provide guidance on how to perform a test or procedure.

A Task Force may run between one and three years with up to 25 members from different countries.

What is a Clinical Research Collaboration (CRC)?

An ERS Clinical Research Collaboration (CRC) brings together stakeholders from across Europe, which may include clinicians, researchers, radiologists, patients, and funding partners to collaborate on a specific area within respiratory medicine.

By sharing knowledge and expertise across different fields, CRC networks help to tackle current challenges and improve future research to improve respiratory health and medicine.

ERS provides initial funding to each CRC so that they can plan activities. Some examples of these are:

- Prioritising research questions and reaching consensus from patients/clinicians.
- Developing networks of expert centres with standardised protocols.
- Co-ordinating existing databases and/or developing new research registries.
- Gaining funding for their activities from industry and EU stakeholders.
- Increasing the number and quality of clinical trials in their field of interest.

A CRC runs for up to three years initially with two Chairs appointed to take the lead for the project.

Why is patient input important?

ERS recognises that patient input into clinical practice guidelines, research and education adds value and can increase the relevance and impact of projects.

Patient input can help to:

- Ensure that any gaps in research evidence that are important to patients are prioritised within research projects.
- Make sure that projects address key issues of concern to patients or that may be overlooked by healthcare professionals.
- Highlight areas where the patient's perspective differs from those of healthcare professionals.

- Underpin guidelines, statements, and research with patient experience,
- Provide input from individuals across Europe to ensure factors such as access, equity and cost are taken into account. This increases the transferability of projects to different settings.
- Ensure that patients will support the outcomes of the project.
- Disseminate the project findings more widely, including to patient groups.

You can read about projects that patients have been involved in previously, such as chronic cough, severe asthma, and smoking cessation for people with lung conditions, on the ELF website: <https://europeanlung.org/en/projects-and-campaigns/list-of-task-forces-and-crcs/>

How are patients involved?

Based on our experience of including patient perspectives in Task Forces and CRCs to date, ELF has developed a [patient input process](#) which you can view on our website.

Patient involvement is discussed between ELF and the Task Force or CRC Chair before the project starts, to ensure that the most appropriate patient involvement activities are included and to complement the aims of the project and its members.

ELF usually recommends that a Patient Advisory Group (PAG) is formed to provide the overall input and steering to the Task Force or CRC. ELF has formed over 10 PAGs linked to different respiratory conditions and individuals can get involved by joining a PAG.

We regularly recruit to our PAGs and members may be a patient, carer or relative of a patient, or a patient organisation representative. Interested individuals should be confident communicating in English, as English is the common language of all ERS activities and communications.

Patient representatives can be involved in a Task Force and CRC in the following ways:

- Joining the Steering Committee to provide input into all aspects from a patient perspective.
- Offering advice on the best way to hear the views of patients.
- Taking part in and helping to develop surveys and focus groups to provide the patient perspective.
- Giving comments on Task Force and CRC goals so that they are relevant to patients.
- Providing input on aspects of living with a lung condition which are important to patients to inform guideline recommendations and future research studies.
- For Task Forces, developing a version of the final document for patients and the public.
- Helping to disseminate the project findings to patients and the public through their networks.

ELF recruits patients through its patient and professional networks, and Task Force and CRC members may also invite their own patients to join the Patient Advisory Group. Two to three patient representatives will be invited to join a Task Force or CRC face-to-face meeting on behalf of the Patient Advisory Group.

As a patient representative, you will contribute the patient perspective to discussions, provide a balance of views and support each other.

An ELF staff member may also accompany you to present an overview of plans for patient input into the Task Force or CRC.

Preparation and training

Even if you have prior experience of working on a clinical practice guideline, on a research project or of sharing your experiences with a group of professionals, ELF will ask you to undertake relevant modules on our European Patient Ambassador Programme (EPAP) www.EPAPonline.eu. This is an e-learning programme for patients and carers to develop basic knowledge and skills in areas of patient representation.

ELF also encourages PAG members to communicate with each other throughout their involvement in a project to share ideas and experiences, and so that you feel comfortable representing yourself and the group at Task Force or CRC meetings.

EPAP is available in Dutch, English, French, German, Italian and Spanish.

How does ELF support you?

ELF has facilitated patient input into ERS Task Forces and CRCs since 2012. During this time, we have developed a range of tools to gather and integrate patient perspectives into clinical practice guidelines and research projects. Our approach builds on best practice in patient involvement and is tailored to the format of ERS projects, for example the GRADE approach to guideline development.

A member of our patient involvement and engagement team will be your named contact throughout your involvement as a patient representative in a project and will provide information, guidance, and support.

We also manage the confidentiality and conflicts of interest process for patient representatives involved in ERS projects and you will be asked to sign a form relating to this if you choose to get involved.

Covering your costs

Your involvement in ERS activities and projects is a voluntary role. You will be reimbursed for any travel and accommodation costs.

Further information

If you would like to get involved or have any questions, email info@europeanlung.org.