Guide for Chairs: 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.

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 current and potential project Chairs on why patient involvement is beneficial and how to get started.

ELF support for ERS projects and activities

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

We can discuss patient input options with you and provide tailored support to involve patients. On pages 3 - 5 you will find a checklist to take you through each step of the application and involvement process. Please get in touch to discuss how we can best support your activities.

Why involve patients in your Task Force or CRC?

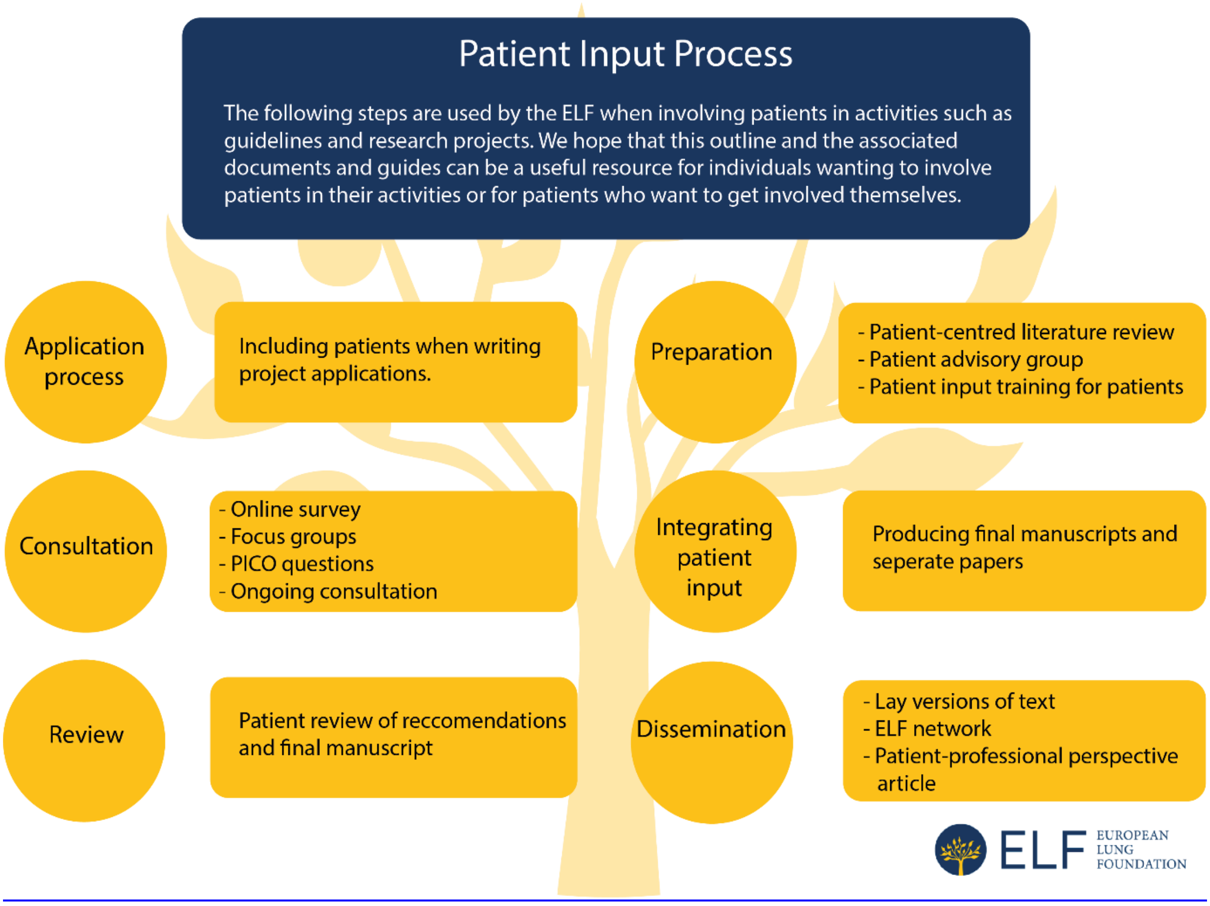
ERS promotes patient and public input into Task Forces and CRCs when appropriate and recognises that this will help to:

- Ensure the gaps in evidence which are important to patients are prioritised within research projects.
- Make sure that guidelines address key issues of concern to patients that may be overlooked by healthcare professionals.
- Highlight areas where the patient's perspective differs from health professionals.
- Underpin guidelines and research with patient experience.
- Provide input from individuals across Europe to ensure factors such as access, equity and cost are taken into account, thus increasing the transferability of projects and findings to different settings.
- Ensure that patients will support the implementation of guidelines and advances in diagnosis and treatment.
- 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 cardiopulmonary exercise testing 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, we have developed a patient input process which can be used as a guide. See diagram below and further details included in this guide.



Patient Input Process

The following steps are used by the ELF when involving patients in activities such as guidelines and research projects. We hope that this outline and the associated documents and guides can be a useful resource for individuals wanting to involve patients in their activities or for patients who want to get involved themselves.

Application process

Including patients when writing project applications.

Consultation

- Online survey
- Focus groups
- PICO questions
- Ongoing consultation

Review

Patient review of reccomendations and final manuscript

Preparation

- Patient-centred literature review
- Patient advisory group
- Patient input training for patients

Integrating patient input

Producing final manuscripts and seperate papers

Dissemination

- Lay versions of text
- ELF network
- Patient-professional perspective article

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 is formed to provide the overall input and steering to the Task Force or CRC. Patient representatives may be a patient, carer or relative of a patient, or a patient organisation representative. If there is already an established patient group connected with the project, then the chairs may prefer to manage patient input themselves via their own group.

Patients can be involved in a Task Force or 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 project 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 finds patients via its patient and professional networks, and Task Force and CRC members may also invite their own patients to join the Patient Advisory Group.

Up to two patient representatives will be invited to join a Task Force or CRC face-to-face meeting on behalf of the Patient Advisory Group. Patient representatives contribute the wider patient perspective to discussions (beyond their own individual experience), provide a balance of views and support each other. An ELF staff member may also accompany the patient representatives to provide support and to present an overview of plans for patient input into the Task Force or CRC.

ELF finds people with experience of lung conditions through our European patient and healthcare professional networks and provides training for them through our European Patient Ambassador Programme (EPAP). This gives the introductory knowledge required to participate in ERS activities with confidence. Free registration for EPAP is at https://elearning.epaponline.eu/

How can ELF support?

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.

ELF provides guidance and practical support to facilitate patient input. This can include, for example, recruitment and ongoing management of a patient advisory group, training and support for patient representatives, and disseminating project results in lay language.

ELF manages the confidentiality and conflicts of interest process for patient representatives involved in ERS projects.

Capacity and costs

ELF works across a large number of ERS and external projects and will balance activities across the portfolio. This may mean that ELF cannot support patient input in certain projects. It is always best to discuss your plans with ELF as early as possible so that we can give you an indication of our capacity to support you.

For Task Forces, ELF staff time and expertise are provided free of charge. Patient surveys are a valuable tool in gathering perspectives from a large number of patients and can often reach a much wider European audience. They do however require a significant investment of staff time and also require budget for translation. If you are considering a patient survey as part of your Task Force, please discuss this with ELF as early as possible. You are advised to include the costs of survey translation within your project budget.

For CRCs, ELF operates a tiered charging structure. Please discuss your project plans with ELF as early as possible.

Checklist for project Chairs

Pre-application stage:

- Contact ELF as soon as possible (ideally at the pre-application stage) to discuss potential options for involving patient perspectives in your Task Force or CRC. ELF can give you general suggestions of where patients could add value to your proposed project, and how to budget for their activities. ELF is not able to give tailored advice at the pre-application stage, as ELF is also involved in the funding review process for Task Force and CRC applications.

- Include appropriate budget for patient representatives to attend meetings and for additional activities such as, for example, translation of a patient survey. ELF can provide guidance on costs.

Project launch and ongoing liaison with ELF:

- An ELF staff member will contact you once the Task Force or CRC has started to talk about the patient input options.

- It can be helpful for an ELF staff member to attend the first face-to-face project meeting (and possibly subsequent meetings) to present an overview of plans for patient input into the project and to provide support to any patient representatives in attendance.

- Ensure that your named ELF staff contact is included in all email communications about Task Force or CRC teleconference/meeting dates, minutes and working documents, so that we can keep track and plan for patient input activities.

- Ensure that all project members understand the role of patients in the project and address any initial concerns they may have. We can provide guidance on this and work with you to ensure that patient representatives understand exactly what is expected of them too.

- If patient representative(s) will be attending meetings, we recommend arranging a short teleconference/meeting with the Chairs and the patient representatives beforehand. This is an introductory conversation to help clarify their understanding of the project and reveal how they can best input on the day and after. ELF can arrange and facilitate this call.

Responsibilities for chairs in Task Force and CRC meetings:

- Give an introduction explaining the role of the patient representative(s) and encouraging all Task Force or CRC members to involve them.

- Prompt patients to provide input where appropriate e.g. especially when their views may differ to the professionals' opinion.

- Use natural breaks in the discussions to explain to patients what is being discussed. Debrief with patients after meetings to make sure they have understood the discussions. Consider lay versions of important documents.

- Be aware of some challenges patient representative(s) may face during meetings:
    - May not be used to attending formal meetings.
    - May not feel part of the group initially e.g. scientific members may already know each other well.
    - Unable to participate fully during in-depth scientific discussion.
    - Difficulties in hearing discussions that may touch on sensitive or potentially upsetting issues e.g. mortality rates, serious complications or ineffectiveness of certain treatments.
    - May be unfamiliar with some of the clinical terms and acronyms used. In this case encourage members to explain these or provide a written explanation.
    - May feel there is a power imbalance between their experience as a patient compared to the expertise of professionals and find it challenging to assert themselves.

- Maintain patient confidentiality at all times.

- Involve patient representative(s) in any social events that you are holding alongside the meeting so that they can get to know other project members in a more relaxed setting.

- Give regular feedback to patient representative(s) and ELF on how their involvement is affecting the project.

Next steps and further reading

Please contact the ELF patient involvement and engagement team at info@europeanlung.org to discuss your patient input options further.

To find out how ELF has integrated patient perspectives into previous and current ERS projects, you might be interested in the following further reading:

- The Severe Heterogeneous Asthma Research collaboration, Patient-centred (SHARP) ERS Clinical Research Collaboration: a new dawn in asthma research. https://erj.ersjournals.com/content/52/5/1801671

- New understanding in the treatment of cough (NEUROCOUGH) ERS Clinical Research Collaboration: improving care and treatment for patients with cough. https://erj.ersjournals.com/content/53/5/1900787

- Patient participation in ERS guidelines and research projects: the EMBARC experience. http://breathe.ersjournals.com/content/13/3/194

- Research priorities in bronchiectasis: a consensus statement from the EMBARC Clinical Research Collaboration. http://erj.ersjournals.com/content/erj/48/3/632.full.pdf

You can also find out more at https://europeanlung.org/en/projects-and-campaigns/list-of-task-forces-and-crcs/.