**Considerations for patient surveys**

Surveys can help to gather patient perspectives from a large number of individuals and can increase input from a more diverse range of people.

If you are planning a survey as part of your European Respiratory Society (ERS) Task Force or Clinical Research Collaboration (CRC), it is helpful to bear in mind the following considerations.

**Accessibility and languages**

* Consider whether your survey will need to be translated into a range of languages. By running a multi-lingual survey, you can help to make sure that you hear experiences from people living in different settings (rural, urban), health systems (free or insurance-based healthcare), and socio-economic backgrounds. Budget should be included for translation costs. The core ELF languages for surveys are: English, French, German, Greek, Italian, Polish, Portuguese, Russian, Spanish. Choosing the best languages for your survey will depend on a range of factors, including the aim of your survey, how you plan to disseminate it, and your budget.
* Consider whether an online survey is the best tool to collect information from the specific patient population you are working with – for example, older people may be less comfortable with using technology. Discussion groups or interviews may be more appropriate tools.

**Survey design**

* Remember that surveys can be used in a variety of ways – for example to collect qualitative data, by asking for patients’ views and experiences using open-ended responses; to collect quantitative data, by asking patients to rate or prioritise statements; to collect a mixture of qualitative and quantitative data.
* Try to keep your survey as short as possible and make sure that your questions and answer choices are clear and unambiguous.
* Avoid jargon, spell out any acronyms and explain any complex medical terms.
* Involving patient representatives in the design of your survey is important, and ELF can help to facilitate this. Patient input at the design stage can help to ensure that the questions make sense and are accessible to your target audience.

**Ethics**

* European Respiratory Society and European Lung Foundation recommend project chairs approach their institution’s ethics committee for an indication of whether ethical approval is required. Ethics rules for surveys vary in different countries and the decision on whether or not ethical approval is required will depend on the aim, content and recruitment methods.
* Consider data protection legislation and how data will be collected, stored, analysed and shared.

**Support from European Lung Foundation (ELF)**

* ELF can help to facilitate patient surveys, as part of our support for ERS Task Forces and CRCs. The level and type of support will depend on ELF capacity and role within the project, but may include development and management of the survey, online hosting, dissemination and analysis. Some costs may need to be covered by the project budget – please see ‘ELF Levels of involvement in CRCs’ for more details. Chairs should discuss their plans with ELF as early as possible when planning the project.
* ELF uses [SurveyMonkey](https://www.surveymonkey.com/) to facilitate online surveys.
* ELF disseminates surveys through its patient organisation network. Task Force and CRC members are also encouraged to share surveys within their local and national patient and professional networks in order to maximise the response rate. ELF can provide multi-lingual information materials to support dissemination.

**Using survey data**

Data collected from patient surveys can inform Task Force and CRC activities and should be incorporated into publications. This can take a variety of formats, including as a ‘patient perspectives’ section in the manuscript, embedded within each clinical practice guideline recommendation, and as a standalone publication.

Remember the importance of patient and public access to research outcomes. ELF can work with you to produce a lay summary of your survey results.

Consider following-up with survey respondents to share a summary of your results.

Consider publishing in open-access journals.

**Examples of previous published surveys**

Details of previous patient surveys are available in the following publications:

* Patient experience of spirometry testing: [ERS/ATS Statement](https://www.atsjournals.org/doi/10.1164/rccm.201908-1590ST) and in-depth [patient preferences paper](https://openres.ersjournals.com/content/7/1/00712-2020).
* [Patient experiences of pulmonary rehabilitation](https://openres.ersjournals.com/content/4/4/00085-2018).
* [Research priorities in bronchiectasis – patient and professional consensus.](https://pubmed.ncbi.nlm.nih.gov/27288031/)
* [ESR/ERS statement paper on lung cancer screening](https://erj.ersjournals.com/content/55/2/1900506?etoc).
* [What is important for people with nontuberculous mycobacterial disease? An EMBARC-ELF patient survey](https://openres.ersjournals.com/content/7/1/00807-2020)