 

ERS Task Force (TF-add number) [Title of TF]

This x-year project runs from [date – date] and the aim is to produce a published document including recommendations in the *European Respiratory Journal* at the end of the project.

The chairs of this Task Force are [names of chairs].

Read more about the guideline development process below and the points where patient input is most needed.

What is a guideline?


Guidelines are recommendations for all healthcare professionals on the best way to treat and care for people with specific conditions. They are based on the best research on a particular topic, and as the name suggests, they are ‘guidance’ and health providers are not legally obliged to follow them.

Why do we need guidelines?



As guidelines are based on the evidence available, they should increase quality and consistency of care. They aim to weigh up all the different factors and options to agree the ‘best’ approach and outline the care that is suitable for most people in that situation.

It is important that guidelines are updated when new evidence is available about safety, new treatments and techniques.

How are guidelines developed?

There are different ways to develop a guideline which include:

* Expert consensus: a group of experts discuss and debate the best ways of treating a condition.
* Survey of clinicians: a small group of experts identify key issues then send out a survey to a large number of doctors and health professionals working in that area. Majority responses are used to create the guideline.
* Systematic review - Gold standard approach – the ‘best’ way
This is the method that European Respiratory Society (ERS) uses:
* Identify all research on the topic published within a set time.
* Evidence is then analysed to categorise it.
* Resulting guideline is based on the best available evidence of what interventions are most likely to benefit patients.

What should a guideline cover?

Individual conditions can have guidelines covering a wide range of aspects – diagnosis, treatment, long-term management.

To make it manageable to produce and for health professionals to actually use, the guideline should not try to cover all aspects of a disease.

It is common to have multiple guidelines in a single disease area covering different aspects e.g. COPD guidelines cover prevention, diagnosis, severe exacerbations, physical activity. This allows patients and doctors to easily find the bit most relevant to them.

The approach used to develop ERS guidelines:
Grading of Recommendations Assessment, Development and Evaluation (GRADE)



The GRADE approach is the method that the working group will use to develop the ERS guideline you are involved in – this is the gold standard. It is a common, sensible and transparent approach to grading quality (or certainty) of evidence and strength of recommendations. It is now considered the standard in guideline development. More information is available at [www.gradeworkinggroup.org](http://www.gradeworkinggroup.org) and in steps below.

The GRADE process and how patients can add value:

* Step 1 – Formulate the questions
* Step 2 – Select outcomes of interest & rate their importance
* Step 3 – Systematic review
* Step 4 – GRADE the evidence
* Step 5 – Going from evidence to recommendations
* Step 6 – Publishing the guideline

Step 1: Formulate the questions e.g.
The working group will define up to 8 PICO questions e.g.

P opulation Children aged 0-18 with an acute exacerbation of bronchiectasis
I ntervention Treatment with antibiotics
C omparison Compared to no treatment with antibiotics
O utcome Better outcomes for child such as fewer exacerbations, quality of life

*Patient feedback here can help make sure that the final guidelines answer the questions that you want answered.*

Step 2: Select outcomes of interest

* Select outcomes for each PICO question *before* conducting literature review.
* Outcomes should be *importance driven*, not evidence driven.
* Select outcomes important to patients and important for clinicians’ decision-making.
* The outcomes chosen will be used in the literature review.

Step 2: Rate outcome importance

* Rate importance of selected outcomes *before* conducting literature review.
* How important is each outcome for decision-making?
* Patients and clinicians are asked to rate each outcome for importance – from not important, to important, and critical. Only critical and important outcomes will be included in the literature review:



*Patients/carers are the best people to say what outcomes are important when making decisions about your health. Patient input here can help make sure that the final guidelines contain the information needed to make a decision e.g. the factors which you would use to help you, the patient, make a decision about whether or not to have particular treatment or a certain diagnostic test.*

Step 3: Systematic Review

* The healthcare professionals or a librarian recruited to the team will search scientific databases for recent, well-conducted systematic reviews and research studies for each PICO question.
* This search may throw up 1000’s of studies so they are then screened to see which ones will actually answer our question.
* Extract outcomes of interest e.g. the data that we decided earlier was important and critical from our ratings exercise – numbers, percentages will be pulled out of the data for each outcome.
* Meta-analyse, when applicable e.g. a statistical approach to combine results from multiple studies.
* Pool it all together and analyse it as a group.

*This process is an area we don’t really get involved in. By being involved in the first 2 steps, the team will be collecting the information that matters to you.*

Step 3: Additional consultation through focus groups, surveys, Patient Advisory Group

Gathering wider patient experiences may be important at this stage e.g. through a survey, focus groups or patient-centred literature review – this can make sure that experiences that might get missed by the main scientific review are included.

A patient-centred review and/or consultation can build a picture of patients’ experience, challenges and unanswered questions.

Step 4: Grade the evidence

Once the systematic literature review is complete, the evidence collected needs to be assessed to find out how reliable it is.

Evidence tables are created for each PICO question to show results and quality of evidence.

When assessing interventions: Randomised Controlled Trials are the highest quality, down to observational studies which are considered low quality. There are four degrees of evidence quality: high, moderate, low and very low. The level of quality shows how much confidence you can have in the results - can you trust it?

Step 5: Going from evidence to recommendations

The main factors that need to be considered:

* Quality of evidence
* Balance between benefits and harms
* Values and preferences of patients
* Feasibility, equity and acceptability

There are two degrees of recommendations (for or against):

* Strong (“We recommend....”)
* Conditional (“We suggest…)

You can produce strong recommendations from low quality evidence - quality is only 1 of 4 factors listed above.

*Patient input here can help make sure that the final guidelines find a good balance between what clinicians need to make a decision, and what is important to patients e.g. patients are best placed to say how they weigh up benefits and harms, and the values and preferences of patients etc.*

How can patients input?

* Values: is there variability in how patients weigh up benefits and harms? E.g. some patients prefer avoiding harms (side effects) – are there certain groups where this tends to be the same view (children, men?)
* Equity: would this intervention impact unfairly on certain patient groups e.g. is it only accessible in large specialist centres?
* Acceptability: is it acceptable to patients? Do they stick with the treatment? e.g. might include drop-out rate in clinical studies but also adherence to treatment.
* Feasibility: is it possible for patients / health systems to do e.g. some practicalities may limit the use of a recommended intervention e.g. time to do; rural living issues.

NOTE: These areas often have no research evidence – research simply hasn’t been done to answer these questions. The views of key stakeholders, including patients, are essential!

Step 6: Publishing the guideline

Recommendations should be transparent, clear and actionable - for both patients and health professionals e.g:

* + “The panel recommends that… should…”
	+ “The panel suggests to not…”
	+ “The panel recommends that…should not…”

The guideline will be published in a respected scientific journal e.g. European Respiratory Journal.

Where do patients fit into publication?

*Patient perspectives will be integrated into the guideline document (through a literature review, survey findings etc). This might be within the guideline itself or published as a separate complementary publication. Patients can advise on the best ways to raise awareness and disseminate the recommendations to the patient audience. Patients can also help to produce a lay version of the published guideline.*