



Suggested Methodology for ERN RARE-LIVER Position Papers

A position paper offers a comprehensive analysis of the existing literature within a field of study, identifying current gaps or problems. They should be critical and constructive and provide recommendations for future research. No new, unpublished data is presented.

A position paper provides a basis for future work, based on a systematic review with input from key opinion leaders and one or more patient representatives.

The structure usually includes a graphical abstract, keywords, introduction, relevant thematic sections (i.e. diagnosis, pathology, treatment, etc.) patient's perspective, discussion, conclusions, and summary for patients, and future directions. The suggested minimum word count is 4000 words, maximum 6000 and 50-100 references.

Suggested steps in the production of a position paper:

1. Identify a small group to work on the paper including a patient representative and a coordinator for that group.
2. Perform systematic literature search.
3. Define a first draft of +/- 10 relevant questions and prioritise them in order of relevance.
4. Reach out to other opinion leaders (still small group) with the question whether they would like to be involved/contribute, whether they agree with the general approach and to provide feedback on the relevance of the 10 questions.
5. Propose that draft and the list of experts to ERN RARE-LIVER office (ERN.RareLiver@uke.de) who will discuss at next ERN Management Board Meeting. If possible, try to have a fair balance among countries and gender, taking into account of course the expertise and publications. In total, there should be 2 or more ERN rare liver representatives of two different centres of different nationalities in the group, and if possible include adult hepatologists and paediatricians.
6. Assign different topics/questions to experts and ask to provide a first draft to answer one or more of the questions.
7. Put together the individual parts and then have everybody review the draft. Regular online virtual meetings can help to efficiently and critically review the main points of the paper.

Aim: Publish in leading journal and disseminate results.

If possible, use [Guide for Patient involvement in the development of clinical practice guidelines & clinical decision support tools - EURORDIS](#)

Ideally, a patient pathway can accompany the position paper. For more information and guidance, please contact the ERN RARE-LIVER office (ERN.RareLiver@uke.de).

Collaboration with national and international liver societies as EASL and ESPAGHAN is desirable.

It is helpful if the group coordinator issues a timeline for the completion of steps 1, 6, 7 (including virtual meeting dates) and the date of manuscript finalization.