



ERN RARE-LIVER Survey Operating Procedure

a. ERN RARE-LIVER surveys

Recommendations to be specified and considered by authors:

- What is the key scientific question(s)?
- What is the specific target group, who should fill out the survey?
 1. If clinicians are addressed:
 - One representative / centre?
 - Or one adult hepatologist and one paediatric representative?
 - Justify, if more doctors per centre should fill in the survey
 - Should non-ERN doctors also be included? Why?
 2. Patients, parents, caregivers
 - Specify who and why
 - Define language and countries and provide translations (office help only in exceptional cases, and requires native speakers to check accuracy of translations)

Office handling of surveys:

- The survey will be reviewed by the ERN Office
- Office may send survey draft for expert reviews
- Following possible revision final joint decision including definition of appropriate distribution channel (Newsletter, specific e-mail, social media etc.)
- Office will export and distribute the results

b. Non-ERN RARE-LIVER surveys

(i.e., other ERNs, other projects: JARDIN, ERDERA, EURORDIS, etc)

- Assessment of the relevance and importance of the survey by office
- Distribution dependent on assessment, work-load and number of survey requests

In case of conflict, the management board will take a final decision.