



EUPSA NETWORK OFFICE

Network office registry rules

- 1) The primary goal of the Oesophageal Registry (OR) is to enable an individual centre to compare its results with the mean (or median) of the all other anonymized participating centres. With annual reports each centre can use this information to improve quality of care if needed.
- 2) The second goal of the registry is to obtain a large international database which enables retrospective analyses to answer clinical research questions and may be the basis for further randomized trials with appropriate power analyses.
- 3) Each centre that fills in its data of at least 3 consecutive years and includes at least 15 patient data sets, may submit a study proposal to the Network Office. If a center has not enough patients to reach that number, it may share their patients with other collaborating centers (2 – 3) to reach the needed number. However, the Network Office can amend to this limitation in case of well posed, intriguing and important research plans.
- 4) The proposal for the research project must be concise and address a specific question which is relevant for paediatric surgical practice. The proposal is reviewed by a subcommittee which advises the Network Office. The Network Office discusses all submitted proposals. If a proposal is accepted, an analysis of the requested data is done by a statistician at the cost of the applicant(s). The applicant receives the outcome data that can help to answer the study questions. It is expected that the data are used for publication. Centres participating in the OR and fulfilling the same criteria as above are allowed to nominate a co-author of publications for which data of the centre has been used. Under the list of authors of the publication it must be declared that this work has been performed with the support of the EUPSA-Registry.
- 5) To improve quality of care it is necessary to have clinical indicators. These indicators include relevant process or outcome measures and are supposed to differentiate between poor, moderate and good quality of care. Indicators are internal and should never be used for external appraisal. With comparisons of indicators each center can, if necessary, improve the performance.
- 6) A subcommittee of the Network Office defines and updates clinical indicators that allow differentiation between centres. For each centre, comparisons can be made with other centres from countries with a similar infrastructure. If a centre requires advice or help to improve its quality of care it can ask for advice from EUPSA via the Network Office.
- 7) If the EUPSA esophageal registry is aimed to be a success, it is necessary to measure long term outcome too.