

Questionnaire for clinical institutions for rare diseases*

(Please fill in a separate form for each outpatient clinic, if applicable)

*Diseases with a prevalence of 1:2000 or lower (when in doubt, please check www.orpha.net)

1. Name of the outpatient clinic/center (in German AND English)

2. Name and address of the department and hospital

3. Name(s) of the responsible medical expert(s) (please include an e-mail address and whether you want your e-mail published on the Orphanet website or not)

4. Rare disease(s) treated at the outpatient clinic/center

5. How many patients with this disease or group of diseases were treated at your center last year?

Total number of patients seen last year:
Number of new cases last year:
Percentage of patients from other regions of the country:
Percentage of patients from abroad:
Estimated number of expert opinions (advice/second opinion to external clinicians) provided last year:

6. Does your center follow a multidisciplinary/multiprofessional approach?

Please describe briefly the medical disciplines and other medical professions involved:

7. Does your center have cooperations in place to ensure the continuity of care between childhood, adolescence, and adulthood (if applicable)?

8. Does your center have arrangements in place for referrals within your country and from/to other EU countries (if applicable)?

9. Does your center have quality management procedures in place to ensure quality of care (including National and/or European legal provisions), and does it participate in internal and external quality schemes (if applicable)?

If yes, please describe briefly:

10. Do you publish in peer reviewed journals on a regular basis?

If yes, please state the number of publications over the past 5 years:

11. Have you obtained project grants over the past 5 years?

If yes, please describe briefly:

12. Do you participate in systematic clinical data collection (local, national, or international registries)?

If yes, please describe briefly:

13. Do you participate in clinical trials?

If yes, please describe briefly:

14. Do you teach and train in the respective field of rare diseases?

If yes, please describe briefly:

15. Do you cooperate with patient organizations (if applicable)?

If yes, please describe briefly:

16. Does your center have links and collaborations with other centers at national, European or international level?

If yes, please describe briefly: