



Orphanet evaluation criteria for expert centres – Ireland

The Orphanet criteria for evaluation are based on the EUCERD recommendations: Quality Criteria for Centres of Expertise for Rare Diseases in Member States (http://ec.europa.eu/health/sites/health/files/rare_diseases/docs/eucerd_centreexpertise_en.pdf) . Before an expert centre is included in Orphanet, a centre's compliance with these standardized criteria is reviewed and evaluated by the Orphanet Ireland national validator via the Orphanet Quality questionnaire. The criteria assessed by the questionnaire are as follows:

Mandatory criteria

- Q1. Volume of the activity for a specific rare disease/group of diseases
- Q2. Capacity to provide second opinions
- Q3. Capacity for multidisciplinary care
- Q4. If applicable, capacity to organize transition from paediatric to adult care
- Q7. Publication in peer-reviewed journals about the specific rare disease/group of diseases
- Q11. Teaching activities for the specific rare disease /group of diseases

Recommended criteria

- Q5. If applicable, capacity for cross-border referrals
- Q6. Organization of quality management strategies to ensure quality of care
- Q8. Research grants for the specific rare diseases/group of diseases
- Q9. Participation in systematic data collection
- Q10. Participation in clinical trials
- Q12. Links and collaborations with patient organizations
- Q13. Links and collaborations with other centres at a national or international level

Below you will find the Orphanet Quality Form for evaluation of expert centres. A pdf version of this form appears automatically during online Orphanet expert centre registration, or a Word version is available from Orphanet Ireland at orphanet.ireland@mater.ie .

Please note that expert clinical centres which have a Department of Health letter of recommendation as a National Centre of Expertise for Rare Disease do not have to complete this questionnaire.

Further information about rare disease classifications is available from Orphanet Ireland at orphanet.ireland@mater.ie



Please note - If you cannot complete all sections below, those indicated ****** are necessary to achieve Orphanet validation of your service.

Orphanet Quality Criteria Form

Name of Clinic: _____

1. ** How many patients did you see with this disease or group of diseases last year? _____

******Total number of patients seen last year: _____

******Number of new cases last year: _____

******Percentage of patients from other regions from the country: _____

Percentage of patients from abroad: _____

**2. ** Do you provide expert advice/second opinion to
Other clinicians by (mail, telephone)? _____**

Number of expert opinions given last year: _____

3. **Is your centre multi-disciplinary, integrating medical, biological, paramedical, psychological and social needs (such as a rare disease board)?

******Please expand your answer:

4. **Does your centre organise collaborations to ensure the continuity of care between childhood, Adolescence and adulthood, if this is relevant?

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

6. Does your centre have quality management procedure(s) in place to ensure quality of care (including National and/or European legal provisions), and does your centre participate in internal and external quality schemes, if applicable? If yes, please describe:

7. **Does the centre publish peer reviewed publications? _____

Number of publications on the disease(s) over the past five years: _____

Number of abstracts and posters published on the disease(s) over the past five years: _____

8. Have you obtained grants for studies on this disease or group of diseases? _____

9. Do you participate in systematic clinical data collection?

If yes, please describe:

10. Do you participate in clinical trials? If yes, please describe:

11. **Do you teach and train for this disease or group of diseases? If yes, please describe:

12. Do you have links and collaborations with patient organisations?

If yes, please describe:

13. Does the centre have links and collaborations with other centres at national, European or international level?
