



**GUIDELINES FOR POST RELEASE
QUALITY CONTROL OF EXPERT CENTRES**

Thank you for accepting to collaborate in the Post Release Quality Control (PRQC) of the Orphanet published data on expert centres in your country.

Please find below the Orphanet inclusion criteria of expert centres and a few guidelines to help you in the task of PRQC:

Orphanet inclusion criteria of expert centres

- **Definition of expert centres**

An **expert center** on rare diseases is intended for Medical management: a specialised or multidisciplinary centre for a rare disease (or a group of rare diseases) organised for medical management of patients or recognised as an expert centre by health authorities. Centres of expertise mentioned in Orphanet should deliver a service of indisputably higher quality than a standard hospital service in the relevant speciality. This data is intended to contribute to appropriate referrals of patients to expert centres and to ease the process of second opinions between professionals, and to establish reference networks.

An expert centre on rare diseases **is not**:

- A conventional specialised medical department without specific focus on rare diseases, even if it is a reputed one.
- A self-declared centre that does not fulfil the selection criteria.

A **genetic counselling clinic** is: a clinic either for all genetic diseases or for a genetic disease/group of diseases organising genetic counselling.

A **network of expert centres** is:

- A network of expert centres specialised in a disease (or group of diseases) with an official designation by health authorities in a country or specific funding from a well established body
- It can be either national, European or International

A network of centres of expertise **is not**:

- A self-declared network (same hospital or same disease without any funding)
- Clinical centres participating in the same clinical trials
- Clinical centres with expert knowledge in the same field but without official recognition.

- **Selection criteria of expert centres**

For countries having official sources : If centres of expertise have been officially-designated by your Health authorities for a given disease/group of diseases, Orphanet should list only those, and no other expert centre.

For non-official sources : selection criteria are those defined by the EUCERD <http://www.orpha.net/nestasso/EUCERD/upload/file/EUCERDRecommendationCE.pdf>

Guidelines

Please check that the information listed in this mini-directory is:

1) Complete:

- to your knowledge are there relevant expert centres in your country missing from the list? If yes, which ones?

2) Relevant:

- do all the expert centres presented in this directory comply with the Orphanet inclusion criteria (please, refer to the EUCERD-derived questionnaire below where the criteria are listed?
- are there any centres in this directory that do not fulfill these criteria? If yes, which ones?

3) Accurate:

- at the best of your knowledge, do you identify errors in the data (i.e. related to persons, institutions,...)? If yes, which ones?

Please, note your comments besides each centre, or list the changes to be done (centres to be deleted, centres that are lacking...) in a free document.

Addendum: Questionnaire for expert centres

(Fill in a separate form for each clinic)

<p style="text-align: center;">For the Orphanet Coordinator only</p> <p>Checked on (date): _____</p> <p>Validation: <input type="checkbox"/> Yes <input type="checkbox"/> No</p>	<p style="text-align: center;"><i>Return this form to:</i></p> <p style="text-align: right;"><i>Fax:</i> _____</p> <p style="text-align: right;"><i>E-mail:</i> _____</p>
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Form intended for the scientific committee to check whether the expert centre matches the quality criteria defined by the EU Committee of Experts on Rare Diseases (EUCERD) for a Centre of Expertise.

ACTIVITY OF THE EXPERT CENTRE FOR RARE DISEASES (RD)*

*A disease is considered to be rare when it affects less than 1 person in 2,000

Are you officially a centre of expertise?

- Yes => If yes, you do not need to answer the following questions
- No => If no, please answer the following questions

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 (mail, telephone)? Yes No

Number of expert opinion given last year:

3. Is your centre multi-disciplinary, integrating medical, biological, paramedical, psychological and social needs (such as a rare disease board)? Yes No

Please explain your answer:

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4. Does your centre organise collaborations to ensure the continuity of care between childhood, adolescence and adulthood, if it Yes No

5. Does your centre have appropriate arrangements in place for referrals within your country and from/to other EU countries (if applicable) Yes No

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 it participate in internal and external quality schemes, if applicable Yes No

If yes, please describe:

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7. Does the centre publish peer reviewed publications?

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

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

8. Have you obtained grants for studies on this disease or group of diseases? Yes No

If yes, please describe:

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9. Do you participate in systematic clinical data collection? Yes No

If yes, please describe:

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10. Do you participate in clinical trials? Yes No

If yes, please describe:

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11. Do you teach and train for this disease or group of diseases? Yes No

If yes, please describe:

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12. Do you have links and collaborations with patient organisations? Yes No

If yes, please describe:

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

Yes No

If yes, please describe:

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