

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>Return this form to: OrphanetDeutschland</p> <p>E-mail: orphanet@bfarm.de</p>
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For the Orphanet Information scientist: Name and the Cns ID of the centre, associated disease(s)name(s) Orpha number(s):

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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

For the expert: Disease/Group of diseases treated :

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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 this is relevant? 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 level?

Yes No

If yes, please describe:

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