

QUESTIONNAIRE PHASE I

FOR THE RECOGNITION OF REFERENCE CENTRES BY KOSEK

THE CANDIDATE CENTRE

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INFORMATION ABOUT THE CANDIDATE CENTRE

A. Instructions for completing the questionnaire for candidate centres and authorisation

Please answer the questions in the following pages by ticking the corresponding answer for your candidate centre or by giving a descriptive answer in the corresponding field.

All questions correspond to a core criterion in the recognition process of kosek. Therefore, all questions must be answered, either in English, French or German. Incomplete questionnaires will be returned. Your answers should be as precise as possible.

Please use continuous text without line breaks or bullet points, this helps with an efficient evaluation of the forms.

Candidate centres fill in one questionnaire per disease group and can apply for one recognition process.

Please submit the questionnaire with the requested annexes via e-mail (electronic format) and paper format to the following address:

kosek – Coordination of Rare Diseases Switzerland
 c/o unimedsuisse
 Haus der Akademien, Laupenstrasse 7
 Postfach
 3001 Bern
 e-mail: info@kosekschweiz.ch

Please submit the complete application with all related documents by **31st of January 2024**.

Contact information of the candidate centre

1. Name, email, phone number and address of the coordinator/head of the candidate centre

Explanatory note: the coordinator is responsible for the good functioning of the candidate centre and coordinates the clinical health care of patients.

(max. 250 characters)

Authorisation to transfer the following information to Orphanet Switzerland

kosek works in collaboration with Orphanet Switzerland in order to simplify and to document the recognition procedure.

1. Do you allow kosek to transfer your application to Orphanet in order to keep the Orphanet database updated? *(Please tick the appropriate answer)*
 - Yes
 - No



B. General information about the candidate centre

1. Name of the institution(s) responsible for the candidate centre

(max. 250 characters)

2. Name(s) of the medical director(s) or directorate(s) of your institution(s)

(max. 250 characters)

3. Name of the candidate centre for recognition

(max. 250 characters)

4. Address of the candidate centre (including general email and telephone number)

(max. 250 characters)

5. For which diseases / (main) groups of diseases is your **centre** a candidate for recognition? Please list them.

Explanatory note: kosek works with the classification of rare diseases as used in the European Reference Networks (ERNs) and provided by Orphanet. The diseases are listed in the Excel sheet sent as a separate document (see Excel sheet ERN disease group). Please note that the document has different tabs.

If you need help with this specific question, please contact info@kosekschweiz.ch before answering.

ADD A DOCUMENT: Please use **Annex I.1.**

Instructions: For each group or subgroup of diseases (column C or D), please indicate if your centre covers it (by highlighting it in green) or if your centre does not cover it (by highlighting it in red). Whenever possible, please avoid highlighting diseases singularly (column E onwards).



C. Clinical health care within your candidate centre

6. Can your candidate centre ensure multidisciplinary clinical health care for all diseases you are candidate for?

- Yes
 No

a. If no, for which diseases is multidisciplinary clinical health care NOT provided?

(max. 500 characters)

7. Does your centre have a rare disease (RD) board that is specific to the disease group you are providing care for?

Explanatory note: the RD board does not need to be based in your institution. It can be organised within the national network / at a national or international level.

- Yes
 No

8. Are there any specific platforms within your institution that your centre uses to perform all necessary disease-related analyses for diagnosis and medical management?

Explanatory note: the word «platform» is to be understood as an infrastructure within your institution.

- Yes
 No

a. If yes, please tick the platforms that are in place in your institution (several answers possible):

- Biomedical
 Genetic /Genomics
 Pathological
 Laboratories
 Other (please specify):

(max. 250 characters)



9. What coding system does your centre use, to code the patients' diseases? (Several answers possible)

- Orphacode
- ICD-10
- Human Phenotype Ontology (HPO)
- Other (*please specify*):

(max. 250 characters)

10. Does your candidate centre have a written concept for transition, in order to ensure transition of your patients between paediatrics and adult medicine?

- Yes
- No

ADD A DOCUMENT: Add your concept of the transition process (**Annex I.2**). Please see the main recommendations about transition in the toolbox (tool VIII).

11. If the complexity of the disease makes it necessary, does your centre have the required infrastructure (i.e., day hospital) and staff (i.e., a case manager) at your disposal?

- Yes
- No

a. If yes, please describe the infrastructure and staff and how it is organised (including laboratories and genetics)

(max. 2000 characters)



12. During consultations with patients, do professionals in your centre share information about patient organisations with patients? (i.e., brochures, address of patient organisations/groups, etc.)?

- Yes
 No

D. Communication and information

13. Does your centre have a communication system for the rare diseases you provide care for (for example a site on the website of your institution)?

- Yes
 No

14. If yes, which one(s)?

- Internet and intranet
 Newsletter
 Special events
 Other (*please specify*):

b. If no, does your centre plan to establish a structured communication system for the rare diseases you provide care for?

- Yes
 No

c. If yes, please describe which one(s) and in what time-frame.

(max. 250 characters)

E. Continuing training of the candidate centre

14. Does your centre provide continuing training for the group of diseases you are applying for?

- Yes
 No

15. At what level does it provide continuing training? (*Please tick the corresponding answer – several answers possible*)

- local continuing training (i.e., continuing training for the hospital/institutional staff)
 continuing training at a national level, for the health care network?
 continuing training at an international level
 other continuing training offers? (Debates, round tables, etc.) – please specify the type of continuing training:



(max. 250 characters)

ADD A DOCUMENT: Please use **Annex I.3.**

Instructions: List the continuing training given by your candidate centre in the main groups of diseases your candidate centre is covering during the past two years. Please specify the target audience of the training (medical or non-medical staff) and at what level it took place (local/regional, national or international).

16. Does the staff in your centre receive regular continuing training?

- Yes
- No

17. Please specify what kind of training the staff in your centre received (*tick the appropriate answers – several answers possible*)

- local continuing training (i.e., continuing training for the hospital/institutional staff)
- continuing training provided by the national health care network
- continuing training provided at an international level
- other continuing training offers (debates, round tables, etc.) – please specify the type of continuing training.

(max. 250 characters)

ADD A DOCUMENT: Please use **Annex I.4.**

Instructions: List the continuing training your staff has received in the main groups of diseases your candidate centre is covering during the past two years. Please indicate whether the training was provided at a local/regional, a national (i.e., within an existing network) or an international level.

F. Research activities – research projects, registries, grants, etc.

18. Has your candidate centre taken part in research projects for the group of diseases you are applying for **during the last five years**?

- Yes
- No

19. Has your candidate centre taken part in clinical trials for the group of diseases you are applying for **during the last five years**?

- Yes
- No



20. Has your candidate centre received competitive and/or non-competitive grants for research into the group of diseases you are applying for **during the last five years**?

- Yes
 No

21. Has your candidate centre received any national or international award or recognition for the group of diseases you are applying for **during the last five years**?

- Yes
 No

22. Does your candidate centre actively take part in the **Swiss Rare Disease Registry** by regularly entering data?

- Yes
 No

a. If no, please explain the reason(s)

(max. 250 characters)

23. Does your candidate centre actively take part in disease specific registers by entering data?

- Yes
 No

a. In which disease-related registers does your centre actively enter data?

(max. 250 characters)

24. Does your candidate centre actively collect patient related outcomes, feedback from patients, like satisfaction on information, medical services or other aspects?

- Yes
 No

25. If yes, which type of data of patient feedbacks/other stakeholders (patient organisations) or patient related outcomes is collected by your candidate centre?

(max. 250 characters)



ADD A DOCUMENT: Please use **Annex I.5**.

Instructions: List the peer-reviewed publications of your centre in the main groups of diseases your candidate centre is covering for the past five years, the current research projects, biobanks and clinical trials of your centre, the main competitive and / or non-competitive grants and awards/recognitions received in the five last years.

G. Coordination and administration

26. Please describe the structure of your candidate centre (organisation chart, names, functions and work percentage of the regular staff of the centre).

Explanatory note: You may add flowcharts, figures or tables if they help illustrate your answer.

(max. 1000 characters)

ADD A DOCUMENT: If available, please add a description of the structure of your candidate centre (organisation chart, functions and staff of the centre etc.) (**Annex I.6**).

27. What kind of cooperation does your candidate centre pursue with patients' organisations? Please describe the cooperation and name the patients' organisations involved.

(max. 1000 characters)



H. Documentation in Orphanet

28. Are your centre's activities registered in the Orphanet database?

- Yes
- No

a. If yes, please tick which one(s):

- Expert centres
- Research projects
- Clinical trials
- Diagnostic tests
- Patients Registries
- Biobanks
- Networks
- Your centre's cooperation with patient organisations

29. Does your reference centre wish to publish its clinical, diagnostic and research activities in the Orphanet database?

- Yes
- No

Note: The Orphanet Switzerland team might need to contact the coordinator of the centre in case they need a clarification for some of the data.

30. What information measures has your centre set up in order to be found by patients?

- Orphanet website
- Website of your candidate centre
- National network website
- Helpline
- Established specialist(s)
- Specific events (i.e., public presentations, conferences, patient interaction opportunities, etc.)
- Other (*please specify*):

(max. 250 characters)

I. Volume of activity

31. Total number of patients seen last year (absolute number)

(max. 250 characters)



32. Total number of patients seen the year before last (absolute number)

(max. 250 characters)

J. General remarks

33. If you have a general comment or some elements to add to this questionnaire, you may do so in the comment section below:

Explanatory note: *This field is optional.*

(max. 1000 characters)



K. Checklist of the documents about the candidate centre to enclose with the application

Whenever a template is available (see table below), please fill it in for the disease groups the candidate centre applies for to complete your application.

Annex number	Requested information	Template available (yes/no)
Annex I.1	List of the diseases the candidate centre is covering, respectively not covering (<i>please use Annex I.1</i>).	Yes
Annex I.2	Written concept of transition process.	No
Annex I.3	List of the continuing training provided by your candidate centre during the past two years, including target audience (medical/non-medical staff) and level (local/regional, national or international) of the training in the main groups of diseases your candidate centre is covering (<i>please use Annex I.3</i>).	Yes
Annex I.4	List of the continuing training your staff has received during the past two years, including level of training (local/regional, national or international level in the main groups of diseases your candidate centre is covering (<i>please use Annex I.4</i>).	Yes
Annex I.5	List of the peer-reviewed publications of your centre for the past five years, the current research projects, biobanks and clinical trials of your centre, the main competitive and/or non-competitive grants and awards/ recognitions received in the five last years in the main groups of diseases your candidate centre is covering (<i>please use Annex I.5</i>).	Yes
Annex I.6	Description of the structure of your candidate centre (organisation chart, functions and staff of the centre, etc.).	No