

QUESTIONNAIRE PHASE I

FOR THE RECOGNITION OF REFERENCE CENTRES BY KOSEK

THE CANDIDATE CENTRE

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IMPORTANT NOTICE:

Should kosek receive many applications at the same time, we reserve the right to organise our work according to the available resources. In this case, a waiting list would be drawn up by disease group and the applicant centres concerned in these disease groups would be informed accordingly.

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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
email info@kosekschweiz.ch

Please submit the complete application with all related documents by **31st of January 2023**.

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.

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. Name and contact details of the coordinator/head of the candidate centre (email address and telephone)

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)



6. 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.*

Whenever possible, please list main groups of diseases. Please avoid listing diseases singularly (column G and onwards in the attached Excel sheet). If you need help with this specific question, please contact info@kosekschweiz.ch before answering.

ADD A DOCUMENT: Please list the main groups of diseases your candidate centre is covering in a separate document (**Annex I.1**).

C. Clinical health care within your candidate centre

7. 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)

8. 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 have to be based in your institution. It can be organised within the national network / at a national or international level.*

- ☐ Yes
☐ No

9. Is/are there (a) specific platform(s) 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 platform(s) that is/are in place in your institution (several answers possible):

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

(max. 250 characters)

10. 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)

11. 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

(max. 1000 characters)

ADD A DOCUMENT: add your concept of the transition process (**Annex I.2**).

Please see the main recommendations about transition in the Toolbox (tool X)

12. 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

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



(max. 2000 characters)

13. 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

14. 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

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

- ☐ Yes
- ☐ No

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

(max. 250 characters)

E. Continuing training of the candidate centre

15. Does your centre provide continuing training for the group of diseases you apply for?

- ☐ Yes
☐ No

16. 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 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 in a separate document (you can use the template in the Toolbox - tool XIII). 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) (**Annex I.3**).

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

- ☐ Yes
☐ No

18. Please specify what kind of training the staff in your centre received (*tick the appropriate answer(s) – 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 list the **continuing training in the main groups of diseases your candidate centre is covering your staff has received** during the past two years in a separate document (you can use the template in the Toolbox – tool XIII). Please indicate whether the training was provided at a local/regional, a national (i.e. within an existing network) or an international level (**Annex I.4**).



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

ADD A DOCUMENT: please list in one document 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 and clinical trials of your centre, the main competitive and / or non-competitive grants and awards/recognitions received in the five last years. As a possible template see the Toolbox – tool IX (**Annex I.5**).

19. Does your candidate centre have research projects for the specific rare diseases / (main) groups the centre provides for **AT PRESENT**?
- ☐ Yes
- ☐ No
20. Does your candidate centre take part in clinical trials **AT PRESENT**?
- ☐ Yes
- ☐ No
21. Does your candidate centre receive competitive and/or non-competitive grants for research into the specific diseases/ (main) disease groups the centre provides for **AT PRESENT**?
- ☐ Yes
- ☐ No
- a. During the past two years, has your candidate centre received any national or international award or recognition, for the specific rare diseases / (main) disease group it provides for?
- ☐ 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)



G. Coordination and administration

- 23.** 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**).

- 24.** What kind of cooperation does your candidate centre pursue with patient organisations? Please describe the cooperation and name the patient organisations involved.

(max. 1000 characters)



H. Documentation in Orphanet

25. 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

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

- ☐ Yes
☐ No

Explanatory note: The adding of information about these activities is voluntary. It allows Orphanet to publish the information about your joint clinical, diagnostic and research activities into its database. Please use the separate template to describe your activities (see Toolbox - tool IX). The Orphanet Switzerland team might need to contact the professional in charge in case they need a clarification for some of the data.

a. If yes, please list and describe the activities in a separate document.

ADD A DOCUMENT: Voluntarily you can add a document enlisting the activities of your candidate centre concerning research projects, patients registries, biobanks, etc. in order to publish them in the Orphanet Database (**Annex I.7**, see template in the Toolbox – tool IX).

I. Volume of activity

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

(max. 250 characters)

28. Number of new patients seen last year (absolute number)

(max. 250 characters)



J. General remarks

29. 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

- | | |
|-----------|---|
| Annex I.1 | List of the diseases the candidate centre is covering
(see <i>Excel sheet of the ERN disease group</i>) |
| Annex I.2 | Written concept of transition process |
| Annex I.3 | List of the continuing training provided by your candidate centre during the past two years, including target audience of the training and level (local/regional, national or international) in the main groups of diseases your candidate centre is covering
(See <i>template in the Toolbox – tool XIII</i>) |
| 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
(See <i>template in the Toolbox – tool XIII</i>) |
| Annex I.5 | List of the peer-reviewed publications of your centre for the past five years, the current research projects 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 |
| Annex I.6 | Description of the structure of your candidate centre (organisation chart, functions and staff of the centre etc) |
| Annex I.7 | Voluntary List of the activities of your candidate centre concerning research projects, patients registries, biobanks, etc in order to publish them in the Orphanet Database
(See <i>template in the Toolbox – tool IX</i>) |