

QUESTIONNAIRE PHASE I

FOR THE RECOGNITION OF REFERENCE CENTRES

THE NETWORK

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Date: 2023

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A. Instructions for completing the questionnaire

This questionnaire is to be completed for one group of diseases by the national network, respectively its committee or its national coordinator. **One copy should be submitted per group of diseases**, as a complement to the questionnaires for candidate centres in the recognition process.

Please answer the questions in the following pages by ticking the corresponding answer for the national network 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.

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**.



B. General information about the network

1. For which diseases / main groups of diseases is your network responsible?

Explanatory notes: 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 II.1**.

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

2. Please describe briefly the specificities of the disease group in Switzerland.

Give information about the estimated prevalence in Switzerland, the estimated incidence in Switzerland, the diagnostic and therapeutic possibilities, the most frequent diseases in this group, the approximate age of onset of the diseases, the life expectancy.

(max. 2000 characters)



C. Network communication and information

3. Does your network have an own website describing its organisation, activities and members?

- ☐ Yes
- ☐ No
- ☐ Under construction

4. If yes, please indicate your network-website:

(max. 100 characters)

D. Continuing training within the network

4. Does your network provide continuing training in the main groups of diseases the network is covering?

- ☐ Yes
- ☐ No

5. At what level does it provide continuing training in the main groups of diseases the network is covering? *(Please tick the appropriate 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. 500 characters)

ADD A DOCUMENT: Please use **Annex II.2.**

Instructions: List the continuing training given by the network in the main groups of diseases your network 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 (regional/local, national or international level).



E. Coordination and administration of the network

6. Please describe the functioning of the national network in terms of frequency of meetings and main contents of the meetings

(max. 1000 characters)

7. Please give the name, email, phone number and address of the network coordinator.

(max. 500 characters)

8. Please provide a list of the members of the national network, including patients' organisations.

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

Instructions: List the members of the network.

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

Instructions: Add the commitment letter from your network signed by the president of the network and one or more patients' associations.



F. Checklist of the documents for networks to enclose with the application

| Annex number | Requested information | Template available (yes/no) |
|-------------------|---|-----------------------------|
| Annex II.1 | List of the diseases the candidate centre is covering, respectively not covering (<i>please use Annex II.1</i>). | Yes |
| Annex II.2 | List of the continuing training provided by the network during the past two years, including target audience (medical/non-medical staff) and the level (regional/local, national or international) of the training in the main groups of diseases the network is covering (<i>please use Annex II.2</i>). | Yes |
| Annex II.3 | List of the permanent members of the networks and their function/role within the network (<i>please use Annex II.3</i>) | Yes |
| Annex II.4 | Commitment letter from your network signed by the president or the coordinator or the responsible person of the network and one or more patients' associations (<i>see template in Annex II.4</i>) | Yes |