



QUESTIONNAIRE PHASE I

FOR THE RECOGNITION OF REFERENCE CENTRES

THE NETWORK

Author: Coordination Rare Diseases Switzerland (kosek)

Date: 2022

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.

Table of content

BRIEF DESCRIPTION OF THE NATIONAL NETWORK	2
A. Instructions for completing the questionnaire	2
B. Network information	3
C. Network communication and information.....	4
D. Continuing training within the network	4
E. Coordination and administration of the network.....	5



BRIEF DESCRIPTION OF THE NATIONAL NETWORK

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
email info@kosekschweiz.ch

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



B. Network information

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

ADD A DOCUMENT: Please list the diseases the network is covering in a separate document (**Annex II.1**)

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.

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

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

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, etc.

(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

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 list the continuing training given by the network during the past two years in a separate document. 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) (**Annex II.2**). See template in the Toolbox (tool XIV).



E. Coordination and administration of the network

6. Does your network have a legal form?

- Yes
- No

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

(max. 1000 characters)

8. Please provide a list of the members of the national network, including patients organisations. Please give the coordinates of the network coordinator.

ADD A DOCUMENT: Please list the members of the network in a separate document. You may use the attached template (**Annex II.3**)

ADD A DOCUMENT: Add the commitment letter from your network signed by the president of the network and (at least) one patient association (**Annex II.4**, see templates in German and in French in the Toolbox (tool VI or tool VII). Please add your letter in one of these languages or in English.)



Checklist of the documents for networks to enclose with the application

- | | |
|------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Annex II.1 | List of the diseases covered in the network (see Excel sheet ERN disease group) |
| Annex II.2 | List of the continuing training provided by the network during the past two years, with specification on the target audience (medical, non-medical staff) and the level of the training (regional/local, national or international level) in the main groups of diseases the network is covering. See template in the Toolbox |
| Annex II.3 | List of the permanent members of the networks and their function/role within the network. See template in the Toolbox |
| Annex II.4 | Commitment letter from your network signed by the president or the coordinator or the responsible person of the network and (at least) one patient association (see templates in German and in French in the Toolbox, as one possible example – tool VIII). Please add your letter in one of these languages or in English) |