



QUESTIONNAIRE II

FOR THE RECOGNITION OF REFERENCE CENTRES

DESCRIPTION OF THE NATIONAL NETWORK

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A. Instructions for completing the questionnaire

All questions must be answered, either in English, French or German. Incomplete questionnaires will be returned.

* = core criterion: A list of the core criteria is available in the Toolbox - Tool XI.

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 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

info@kosekschweiz.ch

Please submit the complete application with all related documents by 31st March 2021.



B. Network of the centre and scope of medical service provision

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. If some diseases are not cared for in the network, to which institutions/ specialists are these diseases / main groups of diseases in your given ERN classification transferred?

Explanatory note: in the previous question you listed the diseases / main groups of diseases the network provides care for. In this question we would like to know how the whole disease group along the ERN classification is organised in Switzerland (i.e. to which expert(s) does the network send patients with a disease it does not provide care for?).

(approximately. 1000 characters)



3. Please describe the scope of medical service provision for your disease group. * CORE CRITERION

Explanatory note: the group of diseases should correspond to the ERN disease groups. If this is not the case, please specify in question 1 and 2 which diseases are covered in your network.

Give information about:

a. the needs and specificities of the disease group

(app. 2000 characters)

b. the estimated number of patients within the disease group in Switzerland

(app. 1000 characters)



- c. the health care services (geographic and linguistic) offered, and any known shortfalls in the medical service provision

(app. 2000 characters)

4. Please describe the health care network that is specific to your group of diseases. *
- CORE CRITERION**

Please describe as precise as possible.

If there is a standard description for the network (that has been developed by the network), please include it. You may also add tables or figures, etc., in order to better explain your answer.

Explanatory notes: the group of diseases should correspond to the ERN disease groups. If this is not the case, please specify in questions 1 and 2 which diseases are covered in your network.

It is highly recommended to add a standard description of the network that has been developed and coordinated within the network, between the members of the network, and which tackles all of the following points. You may also find useful instruments for describing the care situation and the network in the Toolbox (Tools I - V). The setup of the network also includes a commitment to cooperation (e.g. templates in the Toolbox – Tools VI and VII)

ADD A DOCUMENT: Add the description of the network (if available) or at least a flowchart of the permanent members of the networks and their roles within the network (**Annex II.2** – you can add more than one document).

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.3**, 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.)



a. Which actors are part of the network?

(app. 1000 characters)

b. How it is the network organised (who is responsible for what) and what are the roles of the actors within the network

(app. 1000 characters)

c. How do members communicate with each other?

(app. 500 characters)



d. What topics are discussed within the network?

(app. 500 characters)

e. How is health care organised in Switzerland within the network (geographic and linguistic coverage)?

(app. 1000 characters)

f. How are decisions made within the network?

(app. 500 characters)



g. Please indicate if there is a specific budget available for the network and how it is funded.

(app. 500 characters)

h. For diseases that are not covered in Switzerland, please name which institution(s) patients are sent to and how.

(app. 500 characters)



5. Please describe how the national NETWORK ensures multidisciplinary clinical health care for its patients for * **CORE CRITERION**

a. Diagnostics and therapy

(app. 1500 characters)

b. Follow-up of the patient

(app. 1500 characters)



6. Please describe how multidisciplinary clinical health care is ensured at an INTERNATIONAL LEVEL for patients for * **CORE CRITERION**

a. Diagnostics and therapy

(app. 1000 characters)

b. Follow-up of the patient

(app. 1000 characters)



7. Does your network follow national or international guidelines for the clinical health care of your patients?

- ☐ Yes
- ☐ No

a. Please list them and specify if they are national or international.

(app. 500 characters)

8. Does your network participate in the preparation of national or international guidelines for the clinical health care of your patients?

- ☐ Yes
- ☐ No

a. Please list them and specify if they are national or international.

(app. 500 characters)



9. What forms of cooperation does your network pursue with patient organisations? Please describe the cooperation and name the patient organisation involved.

(app. 1000 characters)

10. For newly diagnosed patients, does your network organise exchange/counselling opportunities with other patients and/or patient organisations, if they are available?

- ☐ Yes
☐ No

Explanatory note: The diagnosis of a rare disease is often a great shock for the patients concerned, their parents and relatives. Interacting with people who have the same disease can help them cope with this shock. The point of view of those equally affected can alter the perspective of the newly diagnosed patient, facilitate the sharing of experience, and reduce stress.

- a. If yes, please name the patient organisation(s) the exchange is organised with and describe the general procedure.

(app. 500 characters)



- b.** If the network does not organise exchange opportunities with patients and/or patient organisations, please explain the reasons.

(app. 500 characters)

- 11.** Does your network have structured communication systems for the rare diseases it provides for, for care partners, or for the wider public? * **CORE CRITERION** (including question 11a)

- ☐ Yes
☐ No

- a.** If yes, which one(s)? *(please tick the appropriate answer(s), several answers possible)*

- ☐ Internet/Webpage
☐ YouTube Channel
☐ Facebook /Twitter /Instagram specific page
☐ Newsletter
☐ Regular column in the mass media: which one(s)? (please specify below)
☐ Seminars or public presentations or conferences
☐ Special events (e.g. rare disease day)
☐ Other (please specify):

(app. 250 characters)



C. Continuing training

12. Does your network provide continuing training? * **CORE CRITERION**

- ☐ Yes
- ☐ No

13. At what level does it provide continuing training? *(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:

(app. 500 characters)

14. Are patient organisations involved in the organisation of the continuing training of the network?

- ☐ Yes
- ☐ No

a. If yes, please describe how they are involved.

(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.4**).



D. Research activities (research projects, registries, grants, etc.)

15. Does your network coordinate research projects for the specific rare diseases/ main groups it is responsible for **AT PRESENT**?

- ☐ Yes
- ☐ No

ADD A DOCUMENT: Please list in one document the peer-reviewed publications of your network for the past five years, the current joint research projects and clinical trials and the main competitive and/or non-competitive grants and awards/recognitions received in the last five years (**Annex II.5**, if applicable).

16. Do disease(s) specific registers exist for the rare diseases/main groups of diseases the network provides care for?

- ☐ Yes
- ☐ No

a. If yes, please list the registers that exist in your field, the diseases each register includes and the website of each register (if available).

Explanatory note: List only the registers currently used within your network or registers for which a future use is planned.

(app. 1000 characters)



E. Documentation in Orphanet

17. Are the actors and activities of your network registered in the Orphanet database?

- ☐ Yes
- ☐ No

a. If yes, please tick which one(s) (*please tick the appropriate answer, several answers possible*)

- ☐ Reference centres
- ☐ Research activities
- ☐ Clinical trials
- ☐ Diagnostic tests
- ☐ Registries
- ☐ Cooperation with patient organisations

18. 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

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

19. Does your network wish to enter joint scientific, clinical, registration and publication activities in the Orphanet Database?

- ☐ Yes
- ☐ No

Explanatory note: The adding of this information is voluntary. It allows Orphanet to include the information about your joint scientific, clinical and registration activities into its database. Please use the separate template (see Toolbox: Tool IX) to describe your activities. If a website already includes this information (e.g. the presentation of your research project on the SNF website), there is no need to complete the fields. The Orphanet Swiss team might need to contact the professional in charge in case they need a clarification for some of the data.

a. If yes, please describe the joint activities as precise as possible in a separate document.

ADD A DOCUMENT: Voluntary information on the joint activities of the network concerning research projects, clinical trials, registers and publications for registration in the Orphanet Database (**Annex II.6**, see template in English in the Toolbox – Tool IX)



Checklist of the documents 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	Description of the network (if available) or at least a flowchart of the permanent members of the networks and their roles within the network
Annex II.3	Commitment letter from your network signed by the president of the network and (at least) one patient association (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)
Annex II.4	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).
Annex II.5	List of the peer-reviewed publications of your network for the past five years, the current research projects and clinical trials of the network, the main competitive and / or non-competitive grants and awards/recognitions received by the network in the five last years (if applicable).
Annex II.6	Voluntary information on the joint activities of the network concerning research projects, clinical trials, registers and publications for registration in the Orphanet Database (see template in English in the Toolbox – Tool IX)