

RECOGNITION PROCESS FOR REFERENCE CENTRES

DOCUMENTATION FOR NETWORKS IN ORDER TO PREPARE PHASE II: OFFICIAL PRESENTATION OF THE NETWORK

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1. Opening remarks about phase II

The overall goal of kosek is to improve health care for affected people. kosek's general approach to do so is to enable stakeholders and networks to cooperate within a national community for the sake of affected people.

Phase II of kosek's recognition process aims to deepen the analysis of the national network during phase I, in order to make a recognition decision based on the information gathered during the whole process.

Therefore, during phase II, kosek aims to get a closer look at how the network is functioning in terms of the five key missions defined in kosek's concept (clinical health care, research, continuing training, information, coordination and administration) and also with regards to national health care coverage of the corresponding group of diseases. Any gaps in health care coverage (for specific diseases or regions) would be identified by kosek and communicated to the national network together with the recognition decision.

During phase II kosek also aims to identify the challenges the network faces in order to have a better view of the disease group. If kosek can help the network with practical tools or by tackling the challenge on a national level with the corresponding partner(s) the network should address it in the meeting in phase II. Conversely, kosek wants to identify good practices that could be shared with other rare disease communities and/or at the national level.

In phase II a virtual meeting is organised between the network representatives and kosek. In phase III a meeting is organised between the candidate centre(s) and kosek. After these phases, kosek evaluates the information gathered during these phases and takes a recognition decision for each candidate centre.

This present document is designed as a support tool for networks to prepare phase II of kosek's recognition process.

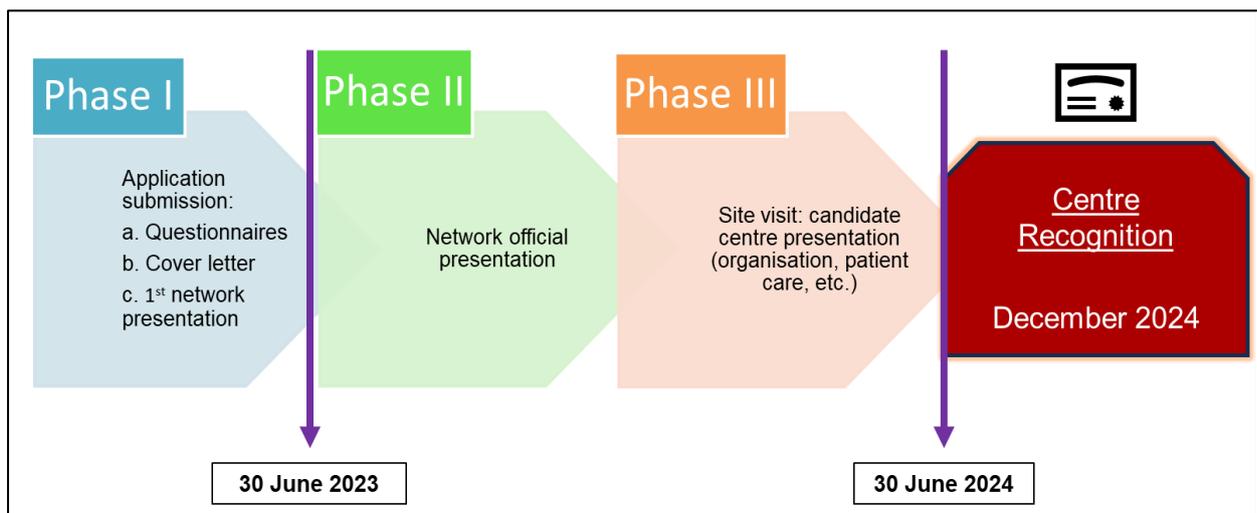


Figure 1: Overview of kosek's recognition process



2. Timeframe for phase II

Due to a large number of applications, kosek had to reorganise its evaluation process. Therefore, phase II of the recognition process takes places as follows:

Step	Responsible actor	Deadline
Information about phase II	Kosek (general office)	31.07.2023
Communication to the network and the candidate centres about kosek's evaluation of phase I. Provision of remaining questions for the network and for the candidate centre. Information about kosek's evaluation delegation	Kosek	31.07.2023
Definition of the meeting date (kosek together with network)	Kosek together with the network	August 2023
Confirmation of the final date of the meeting. Provision of the Zoom-link for the meeting	Kosek (general office)	31.08.2023
Preparation of online meeting	Network	Before meeting
Preparation of online meeting	Kosek's evaluation delegation	Before meeting
Online-meeting	Network and evaluation delegation	Between September and November 2023
Evaluation of online meeting	Evaluation delegation and kosek's evaluation committee	Between November and December 2023
Information to the network about phase II and upcoming tasks (ev. phase III)	Kosek	± February 2024
Ev. phase III	Candidate centres with kosek	± March to June 2024
Information about the official recognition decisions made by kosek	Kosek	± November-December 2024

2.1. Instructions for phase II

In July 2023, the network coordinator(s) will receive the information that the candidate centres successfully passed phase I, an invitation to prepare for phase II and a list of questions to address. The network coordinator(s) will be contacted by kosek's general office to find the ideal date for the online meeting between the network and kosek's evaluation delegation. The network coordinator(s) must be present at the meeting. Ideally one (or more) delegate per candidate centre as well as one (or more) delegate of the patients' organisation(s) should also be present.



The meeting between the kosek delegation and the network delegation will last 60-90 minutes, according to the number of questions that are to be asked the network.

The network must prepare a PowerPoint presentation tackling all questions from kosek. The kosek delegation will ask for precisions or clarification during the meeting, if necessary. The presentation will be sent to kosek (before or after the meeting) in order to have a written document for the evaluation of this phase.

2.2. List of questions to prepare phase II

1. What are the strengths of this network?
2. What are the challenges the network faces at present?
3. What are the specificities of the network?
4. What diseases/disease subgroups of the overall disease group are left out by your network? Which health care provider(s) take(s) care of these?
5. How does the network ensure that it covers all (linguistic) areas of Switzerland?
6. How does the network ensure that all stakeholders that are willing to take part in the network are included? Is there a "risk" that some health caregivers are feeling left out or build a concurring network?
7. Does your network have a legal form? And if yes, what form (please specify)? What tools do you have inside your network (regulation, statutes, charter?)
8. How does your network structure reflect the interdisciplinarity needed by the patients?
9. What is your vision of your network in the future? (Challenges and hypothetical results)
10. How does your network meet the complexity of the disease group?
11. Do you organise regular and official meetings within the network with patients' organisations and health caregivers?
12. What are the qualifying factors in your network that show that collaboration is effective between the actors in the network?

Questions to the network that arose during evaluation of phase I:

Each network that has successfully entered phase II has been sent a list of specific questions.