



European
Reference
Networks

Share. Care. Cure.

ERN Assessment Manual for Applicants

6. Membership Application Form in Active PDF



An initiative of the



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Preamble

This document contains the Membership Application Form in Active PDF. It is part of series of **nine** documents that include the following:

1. ERN Assessment Manual for Applicants: Description and Procedures
2. ERN Assessment Manual for Applicants: Technical Toolbox for Applicants
3. ERN Assessment Manual for Applicants: Operational Criteria for the Assessment of Networks
4. ERN Assessment Manual for Applicants: Operational Criteria for the Assessment of Healthcare Providers
5. Network Application Form in Active PDF
6. Membership Application Form in Active PDF
7. Self-Assessment Checklist for Networks in Active PDF
8. Self-Assessment Checklist for Healthcare Providers in Active PDF
9. Sample Letter of National Endorsement for Healthcare Providers

This series of documents of the Assessment Manual and Toolbox for European Reference Networks has been developed in the framework of a service contract funded under the European Union Health Programme.



APPLICATION TO ESTABLISH A EUROPEAN REFERENCE NETWORK (Membership Application Form)

Instructions

There are **two** application forms:

1. **One** application form with a proposal to establish a European Reference Network, so called the **Network Application Form**, and
2. **One** application form for the Healthcare Providers participating in the above mentioned proposal and willing to become members of the proposed Network, so called the **Membership Application Form**.

Each Network Applicant must complete one Network Application Form in response to the call for interest for European Reference Networks. Each Healthcare Provider Applicant within the proposed Network must also complete the Membership Application Form and provide a written statement of endorsement from its Member State.

Each completed application form must be accompanied by a completed Self-Assessment. Please refer to the Application Checklist for Networks and Healthcare Providers to ensure that all the necessary steps have been completed prior to the submission of the application to the European Commission.

APPLICATION FORM FOR HEALTHCARE PROVIDERS

I. INFORMATION ON THE HEALTHCARE PROVIDER

1. Network's Name:

2. Healthcare Provider:

Name:

Address:

3. Chief Executive Officer of the Healthcare Provider:

First Name:

Last Name:

Tel:

E-mail:

4. Representative who will participate as a member of the Board of the Network:

First Name:

Last Name:

Title:

Tel:

E-mail:

5. Substitute representative who will participate as a member of the Board of the Network:

First Name:

Last Name:

Title:

Tel:

E-mail:

6. Does the Healthcare Provider participate in a national or regional assessment program?

☐ Yes, at the national level

☐ Yes, at the regional level

☐ No

☐ Not applicable

APPLICATION FORM FOR HEALTHCARE PROVIDERS

If yes, please describe.

II. AREA OF EXPERTISE OF THE HEALTHCARE PROVIDER

7. Please list the specific disease(s), conditions(s) and highly specialised intervention(s) covered by the Healthcare Provider. Specify the Code/ICD/Orphanet classification(s) if available.

APPLICATION FORM FOR HEALTHCARE PROVIDERS

8. Briefly describe the area of expertise and the Healthcare Provider's contribution to care for these patients within the Network. (Maximum 500 words)

APPLICATION FORM FOR HEALTHCARE PROVIDERS

9a. What are the types of services covered by the Healthcare Provider within the Network's area of expertise. (Please select all that apply).

- ☐ Prevention (e.g. genetic screening)
- ☐ Acute care
- ☐ Ambulatory services
- ☐ Diagnostic services (e.g. genetic testing)
- ☐ Interventional therapeutic services
- ☐ Rehabilitation services
- ☐ Social care services
- ☐ Palliative care services
- ☐ Other:

9b. Please provide a summary of the specific treatments and interventions provided by the Healthcare Provider. (Maximum 500 words)

APPLICATION FORM FOR HEALTHCARE PROVIDERS

10. Number of patients with the rare or complex disease(s), condition(s) or highly specialised intervention(s) seen by the Healthcare Provider each year.

Paediatrics*:

Adults:

Both:

(*) Please define the age range for paediatric patients:

11. Please provide the number of patients or procedures managed/performed by the healthcare provider as required by the Network to maintain or improve expertise and experience in the rare or complex disease(s), condition(s) or highly specialised intervention(s). Please reference supporting literature and evidence and provide supporting data or actual numbers over the last 3 years.

Measure (*)	Evidence		
	Year 1	Year 2	Year 3
Minimum number of patients / year at each Healthcare Provider			
Number of active caseload / year at each Healthcare Provider			
Number of procedures / year at each Healthcare Provider			

(*) Please provide evidence to the measures defined by the Network.

APPLICATION FORM FOR HEALTHCARE PROVIDERS

12. Please detail the healthcare professionals, and professional qualifications, in the multidisciplinary team that meets the requirement defined by the Network.

[illegible]

(*) Please provide evidence to the measures defined by the Network.

APPLICATION FORM FOR HEALTHCARE PROVIDERS

13. Please list of the specialised equipment, infrastructure, and information technology used by the Healthcare Provider to support diagnosis, care and treatment for the rare or complex disease(s), condition(s) or highly specialised intervention(s).

Rare or Complex Disease(s), Condition(s) or Highly Specialized Intervention(s) covered by the Healthcare Provider*	Specialised Equipment, Infrastructure, and Information Technology (*)

(*) Please provide evidence to the measures defined by the Network.

APPLICATION FORM FOR HEALTHCARE PROVIDERS

III. CONTRIBUTIONS OF THE HEALTHCARE PROVIDER

13. Please describe the strategies that are in place to ensure care is patient centred and patients are empowered? (Maximum 500 words)

14. Please provide an overview of the organisation, management and business continuity plan of the Healthcare Provider within the Network's area of expertise. (Maximum 500 words)

APPLICATION FORM FOR HEALTHCARE PROVIDERS

15. Does the Healthcare Provider lead and/or participate in research activities for the rare or complex disease(s), condition(s) or highly specialised intervention(s)?

☐ Yes ☐ No

If yes, how many research articles have been published by the Healthcare Provider in the past 5 years?

16. What kind of eHealth and information systems is used by the Healthcare Provider to support the rare or complex disease(s), condition(s) or highly specialised intervention(s)?

17. Has the Healthcare Provider developed or adopted clinical practice guidelines for the rare or complex disease(s), condition(s) or highly specialised intervention(s)? Check all that apply.

- ☐ Yes, guideline(s) have been developed by the Network and/or one of the Healthcare Providers
- ☐ Yes, guideline(s) have been developed in cooperation with a Patient Organisation
- ☐ Yes, guideline(s) have been developed in cooperation with another Working Group
- ☐ Yes, guideline(s) have been developed
- ☐ No, but there are current initiatives underway to develop guidelines(s)
- ☐ No, there are no initiatives underway. Please explain.

APPLICATION FORM FOR HEALTHCARE PROVIDERS

18. Does the Healthcare Provider offer education and training activities for the rare or complex disease(s), condition(s) or highly specialised intervention(s)?

- ☐ Yes, by courses/elective during (medical) education, i.e. pre-graduate, graduate, fellowship
- ☐ Yes, by courses/continuing medical education, namely _____
- ☐ Yes, by courses/continuing education for other healthcare professionals, namely _____
- ☐ Yes, namely _____
- ☐ No

If no, please explain

19. Does the Healthcare Provider collect clinical outcome data on the rare or complex disease(s), condition(s) or highly specialised intervention(s)?

- ☐ Yes
- ☐ Yes, and the information is shared with the Network
- ☐ No, but they are under development
- ☐ No

If yes, please complete the following table, specifying the clinical outcomes collected and provide data for the last 3 years.

APPLICATION FORM FOR HEALTHCARE PROVIDERS

Clinical Outcome (*)	Year 1	Year 2	Year 3

APPLICATION FORM FOR HEALTHCARE PROVIDERS

20. Does the Healthcare Provider record patient data on the rare or complex disease(s), condition(s) or highly specialised intervention(s) within a patient registry?

- ☐ Yes, locally via EHR
- ☐ Yes, locally using separate registration system/database
- ☐ Yes, regionally
- ☐ Yes, nationally
- ☐ Yes, internationally
- ☐ No, but the following activities have been undertaken to set up a (inter) national database
- ☐ No

IV. COMMENTS

21. Is there any other background information that you would like to provide on the Healthcare Provider?

APPLICATION FORM FOR HEALTHCARE PROVIDERS

V. AGREEMENT AND SIGNATURES

Name of the Healthcare Provider:

Having read the call for interest for “European Reference Networks” for rare or complex disease(s), condition(s) or highly specialised intervention(s) and the present application document,

I, the undersigned:

in my capacity as:

- Certify that the information contained in this application is correct;

Sign in (place):

On (date):

Surname and First Name of the Healthcare Provider Representative:

Signature:

Annex III – Application Checklist for the Healthcare Providers



APPLICATION CHECKLIST FOR THE HEALTHCARE PROVIDERS

Healthcare Provider Checklist:

- ☐ The Healthcare Provider has an identified representative
- ☐ The Healthcare Provider has a representative on the Board of the Network
- ☐ The Healthcare Provider completed the application form for Healthcare Providers
- ☐ The Healthcare Provider obtained a written statement of support from its Member State
- ☐ The Healthcare Provider completed the self-assessment for Healthcare Providers with supporting documentation