# Annex 1 Notification form for the Rare Diseases Advisory Group

Internal use only

Reference:

| **Name of healthcare provider** |  |
| --- | --- |
| **Name of NHS Trust** |  |
| **Name and contact details of person completing this form** | Name:Title:Email address: |
| **Name of European Reference Network** |  |
| **Plain Language summary of condition** **(approx. two sentences)** |  |
| **Role** | **Lead** [ ]  **Member[[1]](#footnote-1)** [ ]  |
| **Will you be joining an existing network?** |  |
| **Do you intend to collaborate in establishing a new network?** |  |
| **Are there any other UK Approved Healthcare Providers (AHP) involved?** |  |
| **Please list the other UK Healthcare Providers/AHP** |  |
| **Purpose of joining the ERN** |  |
| **Objectives** |  |
| **Outcomes** |  |
| **Has the allocation of resources been agreed at the appropriate local level?** |  |
| **Confirmation is required that that where English genetic services are provided that the additional requirements laid out in 3.1 (page 10) of the application guidance are met** | **Yes** [ ]  **No** [ ]  **N/A** [ ]   |

European reference networks

Supporting Notes for the completion of Notification form for the Rare Diseases Advisory Group

(Annex 1 to Guidance on the recognition of healthcare providers and UK oversight of applications)

# Purpose of this document

This document provides advice to healthcare providers on completing the Notification form for the Rare Diseases Advisory Group (Notification form), which is Annex 1 to Guidance on the recognition of healthcare providers and UK oversight of applications (Guidance).

Before completing the Notification form, healthcare providers should obtain agreement and approval from their relevant national NHS body (NHS England, NHS Scotland, NHS Wales or Health and Social Care in Northern Ireland). To obtain this approval, healthcare providers will need to demonstrate that they meet the individual country recognised healthcare provider criteria in section 3 of the Guidance. Only once healthcare providers have obtained approval from their relevant NHS body should the Notification form be completed. It is advisable for healthcare providers to share a copy of this completed form with their relevant NHS body for comment prior to submitting the form.

Advice on the information required for each section of the Notification form is below. Once compete, the form should be submitted to the Rare Diseases Advisory Group at ERN.application@nhs.net. Any queries about the completion of the Notification form should be sent to the same email address.

# Name of healthcare provider

This section should state the full legal name of the healthcare provider.

# Name of NHS Trust

This section should state the full name of the relevant NHS Trust.

# Name of European Reference Network

If the healthcare provider is proposing to establish a new ERN, the proposed name of the ERN should be stated.

If the healthcare provider is seeking to join an existing ERN, this section should state the full name of the ERN.

# Role

This section should indicate whether the healthcare provider is proposing to lead the relevant ERN or join as a member. The words 'Lead' or 'Member' should be deleted as appropriate. Note: the 'Lead' healthcare provider is referred to as the 'Coordinating Member' in EU documentation.

# Existing or proposed membership of ERN

The healthcare provider should have in-principle agreement with the proposed members of the ERN on the purpose and objectives of the ERN before submitting this form.

If the intention is to establish an ERN, this section should detail the proposed membership, noting that each ERN must have at least ten healthcare providers from eight Member States.

If the intention is to establish an ERN or join an existing ERN, information on any proposed or existing UK members of the ERN should be included, be they collaborating partners or others.

This section should also state if you intend to be an Affiliated Partner.

# Purpose of joining the ERN

This section should detail why the healthcare provider would like to establish or join the ERN, including any special expertise of the healthcare provider, the expected contribution of the healthcare provider to the work of the ERN and the expected benefits to UK patients.

If the healthcare provider is proposing the establishment of a new ERN, this section should also explain why a new ERN is needed to carry out this work, including how the proposed ERN will differ from existing ERNs and how it will collaborate with existing ERNs to achieve the overall objectives of the ERN programme.

# Objectives

If the healthcare provider is proposing the establishment of a new ERN, this section should detail the objectives of that ERN and how they meet the requirements of Art 12(2) of Directive 2011/24/EU, which are replicated in section 1 of the Guidance.

If the healthcare provider is seeking to join an existing ERN, this section should detail how its contribution will further the specific objectives of that ERN and support better care for UK patients.

# Outcomes

If the healthcare provider is proposing the establishment of a new ERN, this section should detail the expected outcomes or outputs of that ERN. It should also specify any deliverables. For example, if the proposed ERN expects to produce good practice guidelines on a particular topic, or establish a new training programme, this should be detailed here.

# Resources

This section should detail the resources available to the healthcare provider to fulfil its role as lead or member of the ERN. Resources should be agreed at the local level prior to the completion of this form.

1. Delete as appropriate [↑](#footnote-ref-1)