*: update 26032021

Application Form *

1. Application Details

Before you start, please check the following:
-The rare disease coordinator of your hospital has provided you with the questionnaire that forms the basis for this online full application and the relevant formats 1-5. In preparation for this online application you have gone through these documents once in order to find out which questions you can expect.
-He/she also provided you the Official Application Letter of the Executive Board of your Hospital to the Ministry of VWS, which you will have to upload in the system.
-In preparation for this online application you have filled out the formats 1-5 you need to upload and you have gathered all the relevant care-pathway documents (as PDF, Word, Excel or JPEG/PNG file). You can upload a maximum of 5 care pathways per (cluster of) disorder(s) (2x10MB max + 3x5MB max). These can be in Dutch.
-You have available the numbers of patients that are seen in your center.
-For technical/system questions, please contact zeldzameaandoeningen@nfu.nl
-For content related questions please contact the rare disease coordinator of your hospital.
-Please be aware you fill out all questions (in the 10 categories/tabs)
-The rare conditions and Orphacodes cannot be modified as they are fixed based on your pre-application.

1.1 Pre-Application Details	
Application ID:	
Naam 1e contactpersoon	
Email:	
Phone number:	
Applicant health care institution:	
Name Center of expertise in Dutch:	
New candidate EC?	
What is the previous assessment number of the EC:	
Hospital(s):	
Give a short description of the area of expertise and the contribution to care. Max 1500 characters (incl spaces)	
What are the types of services covered by the EC?	

1.2 Is the candidate EC already participating in an ERN?*	

2. Partner Organisation

2.1.1 **Partner 1 - Partner(s):**

2.1.2 **Partner 1 - Please describe how the partner institutions collaborate as <u>one</u> center of expertise (regarding care, research etc.) Max 1500 characters (incl spaces)**

3. Rare Conditions

3.1.1 Rare Condition 1 - Please fill out the questions below for the following (cluster of) rare disease(s) with corresponding Orphacode:	
Name of rare condition or cluster of rare conditions:	
Orphacode:	

3.1.2 Rare Condition 1 - Patient Numbers Seen						
	Last Year Adult	Last Year Paediatric (antenatal-18 yrs)	2 Years Ago Adult	2 Years Ago Paediatric (antenatal-18 yrs)	3 Years Ago Adult	3 Years Ago Paediatric (antenatal-18 yrs)
A. How many patients with the rare condition(s) in question are seen (total per year; visited, treated, followed) by the EC?						
B. Number of patients for first appointment (new patients per year)						

3.1.3 Rare Condition 1 - What is (an estimate) of the prevalence in NL: Fill out: x/10.000 In case of tumours: what is the incidence in NL? Fill out: x/10.000	
Choose Prevalence or Incidence:	

3.1.4 Rare Condition 1 - Is there a minimum number of patients defined by the guideline or standard in order to improve knowledge and experience?*	

3.1.5 Rare Condition 1 - An expertise center is expected to have established care pathways Please upload the relevant care pathway documents for this specific (cluster of) rare condition(s):(max 5)	
The 'European Pathway Association' defined (2017), that a care path is a method for patient-care management of a well-defined group of patients during a well-defined period of time. A clinical pathway explicitly states the goals and key elements of care based on Evidence Based Medicine (EBM) guidelines, best practice and patient expectations by facilitating the communication, coordinating roles and sequencing the activities* of the multidisciplinary care team, patients and their relatives.Also, non-hospital collaboration (extramurale samenwerking) should be described and the patient discussion at MD consultation meetings.*according to local protocols (description of step by step handling)	
Please click 'Save Draft' button at the bottom of this page after each upload is added.	
Upload 1:	
Upload 2:	
Upload 3:	
Upload 4:	
Upload 5:	

De indicatoren voor VWS erkenning van een ECZA (zie VWS beleidsvisie in Staatscourant), geven ook aan wat er aan informatie in een zorgpad verwacht wordt. Advies is om hier goed naar te kijken.

3.1.6 Rare Condition 1 - Are there (inter) national clinical practice guidelines and/or care standards for the rare condition?*

A guideline is a document containing recommendations aimed at improving the quality of care. The content of a guideline is based on scientific research, complemented by the expertise and experience of healthcare providers and patients. Doctors should apply the guideline in their care.

A care standard describes from a patient perspective what quality care must meet. Not only for the content of the care (such as treatment or the prescription of medicines), but also for its organisation and the support of self-management. A care standard is therefore an aid for care provider, insurer and patient.

3.2.1 Rare Condition 2 - Please fill out the questions below for the following (cluster of) rare disease(s) with corresponding Orphacode:

Name of rare condition or cluster of rare conditions:	
Orphacode:	

3.2.2 Rare Condition 2 - Patient Numbers Seen

	Last Year Adult	Last Year Paediatric (antenatal-18 yrs)	2 Years Ago Adult	2 Years Ago Paediatric (antenatal-18 yrs)	3 Years Ago Adult	3 Years Ago Paediatric (antenatal-18 yrs)
A. How many patients with the rare condition(s) in question are seen (total per year; visited, treated, followed) by the EC?						
B. Number of patients for first appointment (new patients per year)						

etc.

4. Quality of care-general

4.1 How many/which staff members are directly/permantly involved in the centre?	
Click to download the Format 1 in case you have not filled it out yet. Please save it as a PDF on your computer and upload it.	
Browse and upload format 1: table of names, specialisms and expertise:	

4.2 Are there regular structured meetings between multidisciplinary (MD) team members? *

4.3 The EC has defined the roles within the MD team in the care pathways and informs the patient and involved parties of this:

4.4 The EC has defined and has informed care providers, patients and their family about the availability of the MD team members for emergency/non-emergency care.

4.5 The EC has taken care of coordinating the entire care pathway, next to the treating physicians *

4.6 Which (extramural) collaboration(s) has the EC established in order to safeguard the entire care chain? (if necessary as shared care) *

4.7 Does the EC use quality indicators that are common to the rare conditions in question? And if quality indicators are available from the ERN, does the EC compare results with those of other ECs?

4.8 Comments about the theme "Quality of care"

5. Transition

5.1	The way the quality of transition from pediatric to adult care is safeguarded is described in the care pathway?

5.2	Comments about the theme 'Transition'

6. Continuity of EC

6.1	Is an alternate available for each discipline involved in the MD team to safeguard the continuity of the EC in case a member drops out or departs? *

6.2	How does the centre provide training of and/or transfer of knowledge to new experts in the MD team? *

6.3	The Executive Board of the health care providing institution supports this application, which thus guarantees continuation of the EC
Upload Letter of Executive Board:	

6.4	Comments about the theme 'Continuity of EC'

7. Cooperation with other parties

Cooperation with other parties

7.1	How does your centre work together with patient organisation(s) in question? *

7.2	Frequency of periodic meetings/alignments

Click 'ADD' after each line of information is input to save data. (Max 10 Patient Organizations)

Name Patient Organisation	Mail Address of Contact Person	Frequency of Contact

7.3	What activities are undertaken with patients/patient organisation(s) to integrate the patient perspective (in research and care) together? *

7.4	The EC works together nationally with other centers of expertise? *

7.5	The EC works together internationally with other centres of expertise? *

7.6	Comments about the theme 'Cooperation with other parties'

8. Information and Communication

The EC functions as a point of information for care providers, patients and their family and friends.

8.1 Does the EC have a specific website/page available for care providers and for patient and family with information about the EC, the rare disease and the Care Pathways? *

8.2 Does the EC have specific brochures/flyers available for care providers and for patient and family with information about the EC, the rare disease and the Care Pathways *	
Please upload:	

8.3 Question is not applicable.	If you answered previous question with 'YES', has the information been developed in collaboration with the patient organisation(s)? *

8.4 Question is not applicable.	you answered question 8.2 with 'YES', is available patient education materials appropriate for readers of varying literacy levels and for speakers of different native languages?

8.5 How often is the centre consulted by other treatment professionals, researchers or patients and family, for example about the diagnosis (second opinion) or treatment (guidelines and new medicines)? *

8.6 Where do these parties come from?

8.7 What is the EC consulted for?

8.8 Is the accessible information available tailored to the specific needs of patients and their family?

8.9 Is there specific information related to (multi)cultural issues included in the described care pathway?

8.10 Does the EC offer education and training for the rare condition(s) to care professionals outside the EC and other professionals outside the health care? *
The centre provides education about the (cluster of) rare condition(s) to care professionals outside the EC and other professionals outside the health care.

8.11 Comments about the theme 'Information and communication'

9. Research

The EC conducts scientific research in the field of the rare condition and publishes on the topic.

9.1 Is there one or more professor(s) affiliated with the EC? *

9.2 What kind of scientific research is performed on the rare condition within the EC (several answers possible)?	
Basic scientific research:	
Translational research:	
Clinical research:	
Clinical (orphan) drug research:	
Social science research:	
Other, namely:	

9.3 How many articles, with EC members in a leading role, have been published about the rare condition(s) over the past 10 years?
getal invullen

9.4 Enclose list of the most relevant publications from the EC in the past 10 years, for the centre as a whole and per specific rare condition
Click to download the Format 2 in case you have not filled it out yet. Please save it as a PDF on your computer and upload it.

9.5 What grant(s) has the EC obtained (as main applicant) over the past 5 years? Browse.. and upload format 3.
Click to download the Format 3 in case you have not filled it out yet. Please save it as a PDF on your computer and upload it.

9.6 How many employees affiliated with the EC conduct scientific research?(table with name, function and scope of research appointment) Browse and upload format 4
Click to download the Format 4 in case you have not filled it out yet. Please save it as a PDF on your computer and upload it.

9.7 Does the EC record patient data on the rare disease? *

9.8 If previous question is answered with yes, please upload a list of data that are registered by the EC .Browse... and upload format 5
Click to download the Format 5 in case you have not filled it out yet. Please save it as a PDF on your computer and upload it.

9.9 Is patient material stored in a biobank? *

9.10 **Does the EC manage the national database?**

9.11 **Comments about the theme 'Research'**

10. Cross-border health care

The EC coordinates and advises on, if necessary, cross-border health care together with specific ECs in other EU countries where patients or biological samples can be referred to.

10.1 **Does the EC discuss patients with experts from accredited ECs within the ERN? ***	
How many per year?	

10.2 **Does the EC refer patients to accredited ECs within the ERN? ***

10.3 **Does the EC receive referred patients from ERN accredited ECs in other EU countries? ***

10.4 **Does the EC send biological samples to ERN accredited ECs within ERNs for diagnostic and research purposes? ***	
How many per year?	

10.5 **Does the EC receive biological samples for diagnostic and research purposes from ERN accredited ECs in other EU countries?**

10.6 **Comments about the theme 'Cross-border health care'**