

Key Information on ERNs for NCP websites



Share. Care. Cure.

NCPs - the key to information in the patient's home country



- **Patients are likely to seek information from their home authority first.**
- **Patients trust information provided by their home authority.**
- **The information is likely to be in a language the patient knows and understands (English may not be the patient's first language).**
- **NCPs can provide information specific to the access of ERNs as the rules apply in that country.**

Create an attractive web page

It's important to create an everyday context for patients seeking to access advice from an ERN. Consider the mechanisms of good communication.

- **Methods of Communication**
- Text. ...
- Images. ...
- Titles and Headers. ...
- Icons. ...
- Design Styles. ...
- Colors. ...
- Audio and Video.



Language



Keep the language simple and use links like “[read more](#)” to provide more detailed and technical information as background.

The more natural the language used the less likely it will be that the patient will have unrealistic expectations of the role and outcome of the ERN engagement.



Know your user, but first know your other stakeholders!

When you start building your ERN web page content, you know who your potential users are. But do you know who the other stakeholders are?

For example:

- The EC – make sure your content reflects the provisions of the Directive and incorporates the many links to information that the EC has developed. Don't reinvent the wheel!
- The ERNs – make sure you include at least a list with links to each of the ERNs so that patients can access information directly from the ERNs.
- Orphan.net – This is a very informative and well structured source of information and I recommend each ERN page includes a link to this website.

These three identified stakeholders are the minimum stakeholders I recommend are included on the webpage. Ideally you would like to include links to other sources of support and information, e.g. disease specific support groups, but that is too vast to be practicably achievable.



Consider the key questions to deliver the key messages:

- Describe the role of the ERN so that the patient does not have any unreasonable expectations of the ERN and the role of the ERN.

Examples of key messages:



- An ERN does not assume responsibility for the patient.
- An ERN's role is to review the patient records and provide feedback.
- An ERN may only be accessed by a patient's treating consultant.
- An ERN is a virtual platform consisting of specialists across Europe working together to provide specialist review of a patient's care on a solidarity basis.

List the ERNs

- Each of the **24 ERNs address** a specific area of intervention, though they also often work together.
- **ERN BOND**: bone disorders
- **ERN CRANIO**: craniofacial anomalies and ear, nose and throat (ENT) disorders
- **Endo-ERN**: endocrine conditions
- **ERN EpiCARE**: epilepsies
- **ERKNet**: kidney diseases
- **ERN-RND**: neurological diseases
- **ERNICA**: inherited and congenital anomalies
- **ERN LUNG**: respiratory diseases
- **ERN Skin**: skin disorders
- **ERN EURACAN**: adult cancers (solid tumours)
- **ERN EuroBloodNet**: oncological and non-oncological hematological diseases
- **ERN eUROGEN**: urogenital diseases
- **ERN EURO-NMD**: neuromuscular diseases
- **ERN EYE**: eye diseases
- **ERN GENTURIS**: genetic tumour risk syndromes
- **ERN GUARD-HEART**: diseases of the heart
- **ERN ITHACA**: congenital malformations and rare intellectual disability
- **MetabERN**: hereditary metabolic disorders
- **ERN PaedCan**: paediatric cancer
- **ERN RARE-LIVER**: hepatological diseases
- **ERN ReCONNET**: connective tissue and musculoskeletal diseases
- **ERN RITA**: immunodeficiency, autoinflammatory and autoimmune diseases
- **ERN TRANSPLANT-CHILD**: conditions and complications linked to the transplantation in children
- **VASCERN**: rare multisystemic vascular diseases
- Source:https://ec.europa.eu/health/sites/health/files/ern/docs/2018_patientsflyer_en.pdf



Provide detail on what happens if the ERN makes recommendations with regard to the patient management. Cover topics like:

- The ERN may concur with the patient's current management.
- The ERN may recommend a different approach to the patient's management and in such a case the patient's consultant will implement the recommendations but always subject to the legislation of the country of treatment and the consultant's clinical autonomy.
- The ERN may recommend referral to a specialist centre for example for an in-person review. In such a circumstance if the patient wishes to avail of an in-person review the patient would access the review under the provisions of the Directive.
- The ERN may recommend a different approach to the patient's management and the patient would prefer to access that service in one of the ERN hospitals. In such circumstances the patient could access that service via the provisions of EU Directive 2011/24/EU or EU Regulation 883/2004 as appropriate and subject to the decisions of the relevant authority in the patient's home country.