

Promoting your European Reference Networks

Communication tips for ERN Coordinators and Members

The European Reference Networks are a new initiative, responding to a societal need and influencing the lives of many patients. **Clear and proactive communication** is needed, showing how European cooperation leads to better treatments, whilst avoiding false expectations or misunderstandings among the patients or partners of the ERN activities.

The driving forces behind the ERNs are healthcare providers and national health authorities. They show trust, take ownership and have the most active role in the development and functioning of the networks. The Commission will support them in providing general multilingual communication material and a narrative to be adapted to their own needs.

The ERN members are invited to **develop and share the concrete and tangible communication stories**. Mutual exchange of all this material will raise the visibility for the initiative, both at the European and the local level.

Narrative

Your main target groups will be health care providers and health researchers; patient organisations and the media. They are the main partners to raise the awareness and knowledge about the ERNs. For each of the three audiences, you will find below some general messages, to be complemented with your specific content and fine-tuned to your local context.

1. Health care providers and health researchers in Europe (non-members ERNs)

Objective:

- Raise medical community's awareness on the existence, the potential and the possibilities offered by ERNs to help addressing complex and rare clinical cases;
- Point out the benefits to them of relying on this expertise;
- Provide guidance on how to access the relevant ERN if they are dealing with a concrete case which needs further scientific and medical expertise.

Key messages:

- The ERNs capture the best expertise and competences to address a patient care, from research to diagnosis and cure, based on the current available knowledge. ERNs benefit from high level capacity building: network support; training (eLearning, access to concrete cases), development of clinical decision making tools, clinical and interdisciplinary research;
- Health care providers can get support to address concrete clinical cases where the knowledge and expertise at their disposal is not sufficient; they can share their own expertise and experience on rare and complex cases; they can have access to advanced resources in research, clinical trials, European registries;
- ERNs are not directly accessible by individual patients: Health care providers connect patients with the relevant ERN national contact point;

- Local health care providers can ask their national authorities for more cooperation at European level through a bottom-up approach.

2. Patients organisations

Objective:

- Raise patients' awareness on the potential benefits offered to them by the European coordination of knowledge and expertise through the ERNs;
- Clarify whom they have to contact/how it concretely works and manage expectations.

Key messages:

- Europe is broadening the field of possibilities to find solutions and support for your disease;
- Show short-term results (and limitations) of active ERNs;
- The patient's first contact point remains their own health care provider.

3. Media (at EU level and in the Member States)

Objective:

- Raise awareness on the existence of the ERNs and on their general objective to improve quality and safety and access to highly specialised healthcare across the EU for patients affected by rare or low prevalence and complex diseases;
- Highlight the EU added value and its concrete impact on citizens' life.

Key messages:

- Show the concrete results of ERN actions, at a European scale as well as within each Member State (incl. figures, e.g. on the number of potential patients, the cost of rare diseases in Europe, etc);
- The European action can support national efforts and provide added value by pooling resources to address isolated cases through an economy of scale; Knowledge is traveling, not patients.

Communication tools

A set of multilingual communication tools (publications, videos, web visuals, etc) are available on the following web page: http://ec.europa.eu/health/ern/toolkit_en.

This material can be used freely by the ERN members and adapted to their specific communication needs.

More communication products will be added on the website in the coming months.

Contact and support

For all content-related questions on the ERN strategy, support in developing your communication strategy, publications, press communication, social media, etc: sante-ern@ec.europa.eu