



EURORDIS Support to European Federations in European Reference Networks of Centres of Expertise



Anna Kole
Health Policy Manager
EURORDIS



CoE and ERN for Rare Disease

Centres of Expertise (CoE)

- are physical structures for the management and care of rare diseases patients at Member states level

But because a CoE for each RD in each MS is unrealistic...

European Reference Networks (ERN)

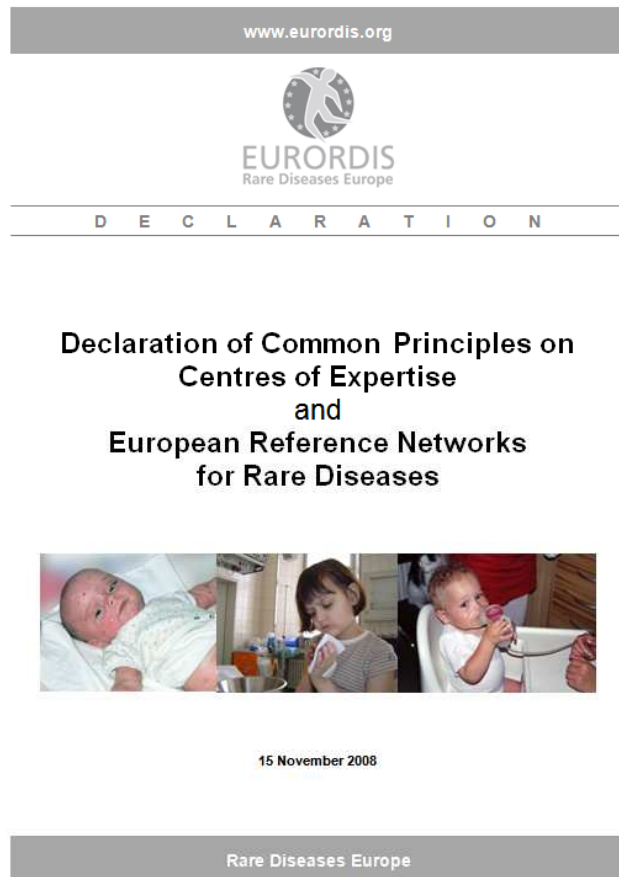
- are the “networking of knowledge and expertise” through either physical or virtual transfer of expertise between CoE for a rare disease or group of rare diseases

EURORDIS past activities for CoE and ERN

Eurordis activities related to ERN 2006 - 2008:

- 2006 Membership Meeting Berlin
- Rare Disease Patient Solidarity Project (Rhapsody, 2006-2008)
- ECRD 2007 Lisbon (session on ERN & CoE)
- Eurordis' Key recommendations and Position paper
- Commission Communication - "Rare Diseases: Europe's Challenges" (2008)
- Declaration of Common Principles on CoE and ERN (Membership Meeting 2008 Copenhagen)
- Council Recommendation on an action in the field of RD (2009)
- European Project for Rare Diseases Plans Development (2008-2011)
- Proposal for Directive on patient's rights in cross border health care
- ECRD 2010 Krakow (sessions on ERN & CoE)

Advocacy Tools for Patient Advocates



Declaration of Common Principles on Centres of Expertise and European Reference Networks for Rare Diseases adopted in order to:

- define ways to improve patient care throughout Europe
- call upon National Health Authorities to endorse, publicise and implement the following Declaration to contribute to the identification of Centres of Expertise, to support them financially, and involve patient organisations in these activities

Fundamental Documents Supporting Their Importance


Council Recommendation on an Action in the Field of RD

- Identify appropriate CoE throughout their national territory by the end of 2013
- Foster the participation of CoE in European Reference Networks
- Organise healthcare pathways for patients suffering from rare diseases
- Support the use of information and communication technologies such as telemedicine
- Include, in their plans or strategies, the necessary conditions for the diffusion and mobility of expertise and knowledge
- Encourage CoE to be based on a multidisciplinary approach to care

COUNCIL RECOMMENDATION
of 8 June 2009
on an action in the field of rare diseases
(2009/C 151/02)

Advocacy Tools for Patient Advocates

EURORDIS POLICY FACT SHEET - EUROPEAN REFERENCE NETWORKS OF CENTRES OF EXPERTISE



EUROPEAN REFERENCE NETWORKS OF CENTRES OF EXPERTISE

A European Reference Network of Centres of Expertise (ERN) is the physical or virtual networking of knowledge and expertise of national Centres of Expertise (CoE) in more than one European country. The goal of a ERN is the improvement in the overall quality and management of care of a single rare disease (RD) or a group of RDs with similar health care needs by complementing, supporting and providing added-value to the existing services and expertise at the national level. Such networking activity between national CoE promotes the sharing and mobility of expertise rather than patients themselves, but permits the travelling of patients to cross-border CoE when necessary. Patients in every European country can benefit from a ERN, although CoE that are members of the network are not necessary in every European country.

WHY ARE EUROPEAN REFERENCE NETWORKS REQUIRED?

The Communication from the Commission, "Rare Diseases: Europe's Challenges"¹ proposes that Member States put in place strategies organised around "ensuring access to high-quality healthcare, in particular through identifying national and regional CoE and foster their participation in ERN".

The Commission's Council Recommendation² on Action in the Field of Rare Diseases accompanying this communication recommends that Member States:

- Foster the participation of CoE in ERN respecting the national competences and rules with regard to their authorisation or recognition.
- Organise healthcare pathways for patients suffering from RDs through the establishment of cooperation with relevant experts and exchange of professionals and expertise within the country or from abroad when necessary.
- Support the use of information and communication technologies such as telemedicine where it is necessary to ensure distant access to the specific healthcare needed.
- Include, in their plans or strategies, the necessary conditions for the diffusion and mobility of expertise and knowledge in order to facilitate the treatment of patients in their proximity.

The European Project for Rare Diseases National Plans Development (EUROPLAN) recommendations³ underscore the importance of Member States to identify national or regional CoE and encourage their participation in ERN.

Article 15 of the proposal of Directive of the European Parliament and of the Council on the application of patients' rights in cross-border healthcare⁴ provides for the development of ERN to be facilitated by the Member States.

WHY ARE EUROPEAN REFERENCE NETWORKS IMPORTANT TO RARE DISEASE PATIENTS?

Due to the large number of RD, to their low individual prevalence, their severity, and to the scarcity of the information about each of them, the field of RD is one in which benefits of collaboration of expertise and maximisation of limited resources are most obvious, especially for ultra RDs in which expertise may only be available in a very small number of European countries. As a CoE cannot exist for each RD in each European country, patients may sometimes need to receive care across borders. The added-value of ERN was put forth by several existing multilateral cross border health care agreements, many European Commission funded projects, documented by the European Commission High Level Group on Medical Care and Health Services, and may be demonstrated more recently by the currently funded EC pilot projects.

1. COM(2008)0079 Communication from the Commission to the European Parliament, the Council, the Economic and Social Committee and the Committee of the Regions on Rare Diseases: Europe's challenges.
2. Council Recommendation of June 2008 on action in the field of rare diseases.
3. CoE recommendations on the development of the national plans for rare diseases 20/ October 2008. Plan recommendations available on the EUROPLAN website: www.europlan-rd.eu
4. COM(2013)0169 Proposal for a DIRECTIVE OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL on the application of patients' rights in cross-border healthcare.

Policy fact sheets supporting the implementation of key recommendations in the European Commission's Communication on Rare Diseases and Council Recommendation on Rare Diseases, and facilitating their transposition into national plans and strategies on rare diseases

Proposed Designation Criteria for ERN

- Professional qualification and clinical and scientific experience
- Commitment to cooperate & share information
- Permits patient's access to a multidisciplinary team of experts
- Importance of coordination between professionals and global approach between medical and social levels
- Agreed best practice, standards and guidelines for diagnosis and treatment
- Dissemination of European reference diagnostic and therapeutic protocols will ensure equity at EU level
- Perform education, information, communication, and activities to empower patients
- **Collaborate with patient organisations**
- ERN should be initially evaluated and accredited at EU level and regularly assessed
- To be aware of the importance of flexibility when selecting the types of centres belonging to the networks and flexibility for geography of the networks.

POLKA project

Polka

Patients' Consensus on Preferred Policy
Scenarii for Rare Diseases

- **Pillar 2: To guide the implementation of the policy on European Reference Networks and National Centres of Expertise**
 - Guidelines on the collaboration between PO's and CoE
 - Guidelines on the collaboration between PO's and ERN
 - Proposal of an evaluation tool by patients and PO's of ERN/CoE

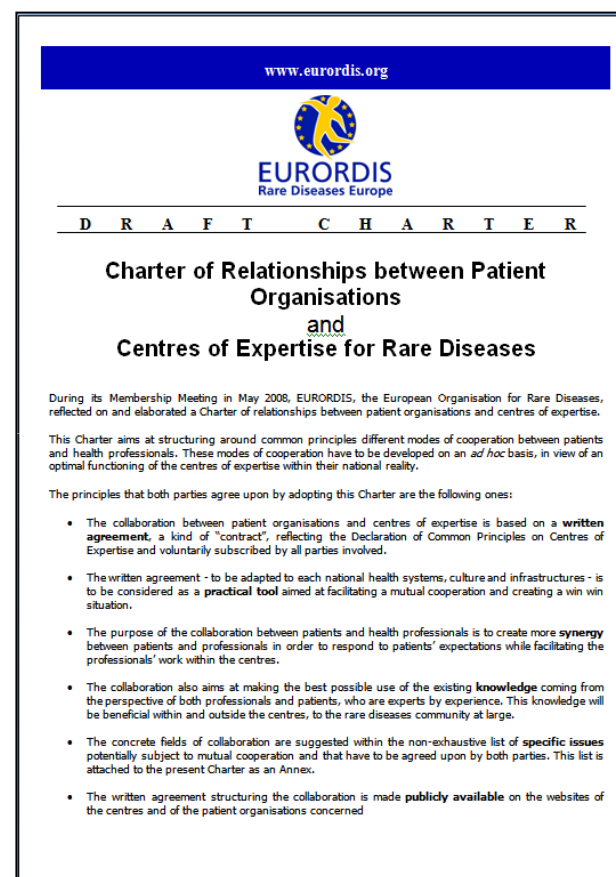
“Collaboration” is not enough....

- **Based on:**
 - circulation of ‘Declaration of Common Principles on CoE and ERN
 - Interviews with PO’s involved in pilot ERN
 - Participation as a patient representative in ERN...
- **The role of PO’s participating in ERN are not clear and therefore limited. The added value of PO’s is often not perceived by clinicians.**
- **EURORDIS would like to go further and propose more specific guidelines for the relationship between PO’s and ERN based on a common set of goals.**

Guidelines for Relationship between PO's and CoE

Use of a practical tool aimed at facilitating cooperation between PO and CoE requires recognition and understanding of CoE as concept.

- Written agreement too binding?
- With whom?
- Sometimes redundant?
- Sometimes difficult to propose?

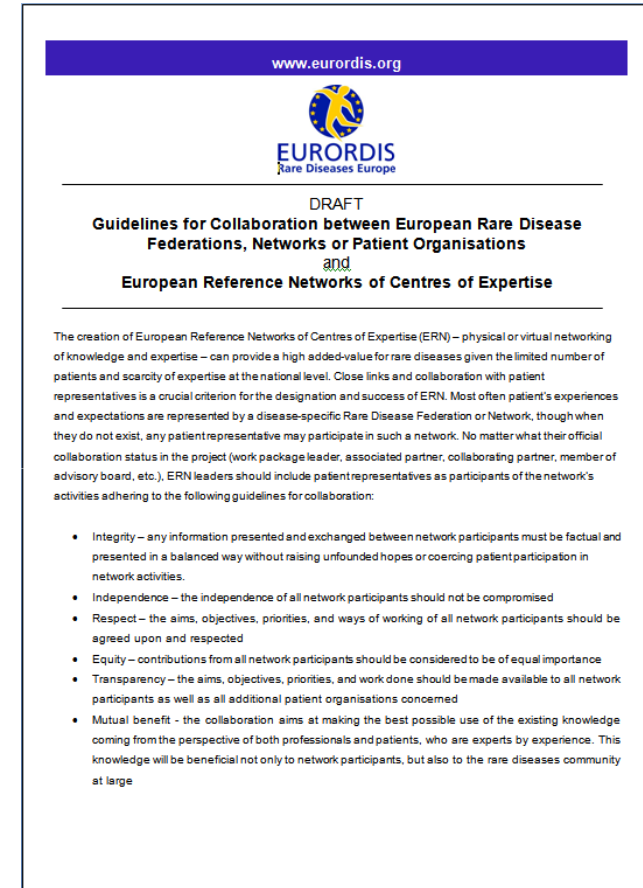


Your input is needed!

Guidelines for Relationship between PO's and ERN

Such collaborations can be further specified in the context of a DG SANCO funded project proposal in which the PO is:

- an associated or collaborating partner and the leader of a WP responsible for representing the expertise and needs of patients (member of Steering Board)
- a member of the larger Advisory Board to represent expertise and needs of patients
- a subcontractor providing expertise from the patient perspective
- a contributor to the activities of the project on a voluntary basis



Your input is needed!

European Projects

- In order for all these guidelines to be implemented and used you need a funded project!
- EURORDIS support of POs involvement in ERN projects includes:
 - Capacity building (tomorrow's workshop, Rare!Together)
 - Creation of guidelines (Declarations and charters)
 - Recommendations (template workpackage, EUCERD)

MORE AND MORE...

European Projects

- EURORDIS is asked to participate in European projects
 - nature (i.e. ERN, registries, research networks)
 - funding agency (DG Sanco, DG Research)
 - levels of collaboration (associated partner, collaborating partner, participant, subcontractor)
 - expectations

EURORDIS in European Projects

- Associated partner in projects addressing cross-cutting issues
- EURORDIS' participation limited to supporting role alongside disease specific patient organisation or federation as official project partners (Collaborating partner or unofficial partner status included in description of work).

EURORDIS in European Projects

- Initial requests:

1. Requests to participate made at least two weeks prior to the project deadline
2. Requests accompanied by a complete project description including specific proposal for EURORDIS' contribution.

- Additional requests:

1. EURORDIS' participation limited to supporting role
2. Maximum encouragement to include disease-specific patient group as WP leader
3. Dissemination of Declaration of Common Principles on Centres of Expertise and European Reference Networks
4. Pilot and improve (DRAFT) Charter of Relationships between Patient organisation and Centres of Expertise

Succes!

More and more patient organisations are at the heart of Commission funded projects each year!