



# CENTRES OF EXPERTISE

Although no official or uniform definition of Centres of Expertise (CoE) exists across Europe, some European countries have established physical expert structures for the management and care of rare disease (RD) patients at the national level. Specialising in a single RD or a group of rare diseases, CoE are care centres that bring together a group of multidisciplinary, specialised competencies. They offer ranges from consultations, medical examinations, specialised equipment, genetic testing and counselling, and social services, to inclusion in research protocols and clinical trials. Managed in a coordinated manner and providing patient-centred services to all patients, they ensure timely diagnosis and appropriate follow-up care and access to social assistance in a setting where patients feel welcome, safe and are received by knowledgeable and understanding professionals.



## WHY ARE CENTRES OF EXPERTISE REQUIRED?

**The European Commission's Communication, "Rare Diseases: Europe's Challenges"**<sup>1</sup>, proposes that Member States establish strategies organised around "ensuring access to high-quality healthcare, in particular through identifying national and regional CoE" and that CoE "may also have an essential role in developing or facilitating specialised social services which will improve the quality of life of people living with a rare disease".

**The Council Recommendation<sup>2</sup> on action in the field of rare diseases accompanying this communication recommends that Member States:**

- Identify appropriate CoE throughout their national territory by the end of 2013, and consider supporting their creation.
- Foster the participation of CoE in European Reference Networks respecting the national competences and rules with regard to their authorisation or recognition.
- Organise healthcare pathways for patients suffering from rare diseases 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.
- Encourage CoE to be based on a multidisciplinary approach to care when addressing rare diseases.

**The European Project for Rare Diseases National Plans Development (EUROPLAN)** recommendations<sup>3</sup> to Member States defines good practice for the designation and evaluation of CoE, their participation in European Reference Networks, and the adoption of international guidelines in the national plans for RD.

## WHY ARE CENTRES OF EXPERTISE IMPORTANT TO RARE DISEASE PATIENTS?

RD patients are subject to marginalisation in classic healthcare systems designed for frequent diseases and as a result are confronted with unequal obstacles. The restructuring of the classic system designed for the management of frequent diseases can be accomplished through the establishment of CoE. The concentration of expertise in a physical structure can bring together a group of multidisciplinary competences, organised around highly specialised medical teams and social service providers.

The consistent establishment, designation, financial support, and evaluation of CoE throughout European countries allows patients and local health care providers to identify high-quality services and benefit from the concentrated expertise by bringing it to the local level. This encourages the travel of expertise between professionals, not of patients themselves. It also allows health authorities to identify the best allocation of financial resources to support the additional activities linked to the duties of these centres. CoE reduce costs in healthcare systems by contributing to shorter delays in diagnosis, less adverse consequences, a reduction in misdiagnoses and subsequent unnecessary treatments and more adequately adapted care.

1 COM (2008) 679 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 8 June 2009 on an action in the field of rare diseases.

3 Draft recommendations for the development of strategic plan for rare diseases including methodological guidance. 28 October, 2009. Final recommendations available on the EUROPLAN website, [www.europlanproject.eu](http://www.europlanproject.eu)

## HOW TO ADDRESS THE ISSUE?

• **The main criteria for the designation of CoE should include:**

- 1 Two essential pre-conditions:
  - a) Professional qualification: both clinical and scientific experience. Proven qualification documented by publications and grants and pre-existing certification or accreditation.
  - b) Commitment to cooperate and share information.
- 2 Patient access to a multidisciplinary team of experts
- 3 Combination of research and care
- 4 Reported volume of relevant activity
- 5 Coordination between professionals
- 6 A global approach (holistic, comprehensive) integrating medical and social aspects
- 7 Participation in research activities at European and international level
- 8 Education, information and communication outreach activities with the public and primary health care professionals
- 9 Training activities for health professionals
- 10 Activities to empower patients and collaboration with patient organisations

Patient organisations should be consulted in the development of a national policy on CoE as well as the establishment, designation and evaluation of CoE.

• **Criteria for evaluation of CoE should be standardised and include:**

Soft values	Hard values
Co-operation with patient organisations	Time to diagnosis
Patient-orientated approach	Waiting time
Improved outcomes	Genetic consultancy
Improved atmosphere	Multidisciplinary approach
Improved quality of life	Co-operation with other centres (clinical and laboratory)
Avoiding unnecessary complications	Registries
Awareness and knowledge dissemination (to patients and to society)	Care guidelines and recommendations
Information provision to local centres	Quality control
	International and national networking
	Economic assessment

## RELATED ISSUES

- The definition of rare diseases, the definition of CoE, and the number and geographical distribution of centres vary in each country, reflecting differences in the organisation of the healthcare systems.
- Centralising expertise may risk minimisation of local expertise or draw expertise away from other centres of care, introduce a lack of trust of local services, reduce coordination in treatment, neglect of psycho-social dimension often addressed at the local level.
- There is always a trade-off between more easily accessible but less specialised services and highly specialised but more remote services.
- Dedicated health professionals interested in a RD do not always guarantee their institutions as CoE.
- Evaluation of CoE should be consistent, but a European-wide evaluation system may infringe on the principle of subsidiarity in Member States.
- What happens to the quality of services for patients seeking care in CoE where the official CoE status is not renewed? If renewal becomes systematic, how to keep centres encouraged improving its practices? Would centres that are not officially recognised as CoE be willing to acquire the competence?
- Maintaining a balance between a CoE strong in research and development versus one focused on clinical care and management is challenging.
- As a CoE cannot exist for each RD in each European country, patients may sometimes need to receive care across borders.

## REFERENCES AND ADDITIONAL INFORMATION

- European Commission Directorate General of Health and Consumers. European Networks of Reference for Rare Diseases. [http://ec.europa.eu/health/ph\\_threats/non\\_com/rare\\_8\\_en.htm#2](http://ec.europa.eu/health/ph_threats/non_com/rare_8_en.htm#2)
- EURORDIS. Declaration of Common Principles on Centres of Expertise and European Reference Networks for Rare Diseases. <http://www.rarediseaseday.org/article/why-rare-disease-day>
- EURORDIS. The Voice of 12,000 Patients: Experiences and Expectations of Rare Disease Patients on Diagnosis and Care in Europe. [http://www.eurordis.org/IMG/pdf/voice\\_12000\\_patients/EURORDISCARE\\_FULLB00Kr.pdf](http://www.eurordis.org/IMG/pdf/voice_12000_patients/EURORDISCARE_FULLB00Kr.pdf)
- EURORDIS. Eurordis Specific Contribution to the Public Consultation: «Rare Diseases: Europe’s Challenges» regarding Centres of Expertise. <http://www.eurordis.org/IMG/pdf/position-paper-EURORDIS-centres-excellence-networksFeb08.pdf>
- EURORDIS. European Workshop on Centres of Expertise and Reference Networks for Rare Diseases Report. Rare Disease Solidarity Project. [http://www.eurordis.org/IMG/pdf/EU\\_workshop\\_report\\_3.pdf](http://www.eurordis.org/IMG/pdf/EU_workshop_report_3.pdf)
- EURORDIS. Policy fact sheet - European references networks. <http://www.eurordis.org>
- Rare Disease Task Force. Centres of Reference for rare diseases in Europe: State-of-the-art in 2006 and recommendations of the Rare Diseases Task Force. [http://www.orpha.net/testor/doc/RDTF\\_anna/WG/StandardsOfCare/reports/RDTFContributiontoEC06FINALVERSION.pdf](http://www.orpha.net/testor/doc/RDTF_anna/WG/StandardsOfCare/reports/RDTFContributiontoEC06FINALVERSION.pdf)