CENTRES OF EXPERTISE

Experience in the area of Centres of Expertise for rare diseases is growing in the European Union's Member States and beyond. Centres of Expertise are a core element of all National Plans on Rare Diseases that the EU Member States are encouraged to adopt by the end of 2013 under the Council Recommendation of 8 June 2009 on an action in the field of rare diseases. Centres of Expertise will also be the main element of all future European Reference Networks on Rare Diseases.
Centres of Expertise (CE) are physical expert structures for the management and care of rare disease (RD) patients. Each CE is specialised in a single RD or group of RDs and share the mission of providing RD patients with the highest standards of care to deliver timely diagnosis, appropriate treatments, and follow up.

The European Union Committee of Experts on Rare Diseases (EUCERD) has issued Recommendations on quality criteria for RD CEs in EU Member States: "CEs bring together, or coordinate, within the specialised healthcare sector multidisciplinary competences/skills, including paramedical skills and social services, in order to serve the specific medical, rehabilitation and palliative needs of rare diseases patients. CEs contribute to building healthcare pathways from primary care."
CEs offer a wide range of specialised services, from consultations, medical examinations, specialised equipment, genetic testing and counselling, as well as social care. CEs also contribute to research efforts through participation in both data collection for clinical research and in clinical trials. They collaborate with different stakeholders, including RD patient organisations.

WHY ARE CENTRES OF EXPERTISE IMPORTANT TO RARE DISEASE PATIENTS?

Each RD affects a small number of patients, and RD patients can become isolated, lost and subject to marginalisation in classic healthcare systems designed for common diseases. As a result, RD patients are confronted with unequal obstacles. RD medical experts, a scarce and precious resource, are geographically dispersed and too often isolated.

The restructuring of the healthcare systems, mainly designed for the management of common diseases, can be accomplished through the establishment of CE. The concentration of highly specialised expertise in a physical structure can bring together multidisciplinary competences, organised around medical teams and social service providers.

The consistent establishment, designation, financial support, and evaluation of CE throughout European countries allow RD patients and local health care providers to identify high-quality specialised services and benefit from the concentrated expertise by bringing it to the local level. This also allows health authorities to identify the best allocation of financial resources to support the activities linked to the management of rare disease patients and other related activities.

CEs 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.

WHY ARE CENTRES OF EXPERTISE REQUIRED?

The European Commission's Communication, "Rare Diseases: Europe's Challenges", proposes that Member States establish strategies organised around "ensuring access to high-quality healthcare, in particular through identifying national and regional Centres of Expertise" and that CE "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 on action in the field of rare diseases accompanying this communication recommends that EU Member States:

- Identify appropriate CE throughout their national territory by the end of 2013, and consider supporting their creation.
- Foster the participation of CE 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 CE to be based on a multidisciplinary approach to care when addressing rare diseases. The European Project for Rare Diseases National Plans Development (EUROPLAN) recommendations to Member States defines good practice for the designation and evaluation of CE, their participation in European Reference Networks, and the adoption of international guidelines in the national plans for RD.

The EUCERD Recommendations on Quality Criteria for CE for Rare Diseases are intended to help EU Member States identify, designate and evaluate CE. The implementation of these Recommendations will help harmonise the quality services offered by CE in Europe and their collaboration at national, European and international levels.

The European Project for Rare Diseases National Plans Development (EUROPLAN) Recommendations to EU Member States reinforces the Council Recommendation and integrates the EUCERD's Recommendations for the designation and evaluation of CE, their participation in European Reference Networks, and the adoption of international guidelines in the national plans for RD.

Criteria for the designation and evaluation of Centres of Expertise

The EUCERD recommends the following criteria for the designation of RD CE by Member States (MS) at national level and their evaluation:

• Designation

MS establish a procedure to define and approve designation criteria and a transparent designation process

1. Capacity to manage RD patients and provide expert advice; adhere to good practice guidelines for diagnosis and care
2. Patient access to a multidisciplinary team of experts (integrating medical, paramedical, psychological and social needs)
3. Assure quality of care, participation in internal and external quality schemes, propose quality of care indicators
4. Proven expertise documented by annual volume of referrals, second opinions, publications, grants, teaching and training activities
5. Participation in research activities, data collection, clinical trials if applicable
6. Organisation of collaborations to assure the continuity of care between childhood, adolescence and adulthood, if relevant
7. Organisation of collaborations to assure the continuity of care between all stages of the disease
8. Collaboration with laboratories, patient organisations, and other CE at national, European, international levels
9. Appropriate arrangements for referrals within individual Member States and from/to other EU countries if applicable
10. Consideration of E-Health solutions

• Evaluation

CE are evaluated on a regular basis through a process incorporated into the designation process at MS level.
The designating authority at MS level may decide to withdraw the designation of a centre of expertise if one or more of the conditions that formed the basis for designation is no longer satisfied, or if there is no longer a need to maintain the national service.

• EU Dimension

CE should be involved in European Reference Networks and organise travel of expertise or cross-border care when appropriate.

EURORDIS and its Members recommend that patient organisations should be consulted at each stage of the development of a national policy on CE as well as the establishment, designation and evaluation of CE. Hard and soft values have been identified by EURORDIS for the evaluation of CE:

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	Care guidelines and recommendations
Information provision to local centres	Quality control
	International and national networking
	Economic assessment

REFERENCES AND ADDITIONAL INFORMATION

- EU Directive on the application of patients' rights in cross-border healthcare
http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:088:0045:0065:EN:PDF
- EURORDIS' position on European Reference Networks
http://www.eurordis.org/publication/european-reference-networks-rare-diseases
- EURORDIS: Declaration of Common Principles on Centres of Expertise and European Reference Networks for Rare Diseases
http://www.eurordis.org/publication/centres-expertise-european-reference-networks-rare-diseases
- 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_FULLBOOKr.pdf
- 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

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