



Centres of expertise for RD: EUCERD recommendations

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Context for EUCERD recommendations

- Centres of expertise and European reference networks are key tools in the EU approach to improve care for patients with RD (Commission Communication, Council Recommendation)
- Recommendations based on iterative discussion and elaboration in Rare Disease Task Force and subsequently EUCERD

Aim of EUCERD recommendations:

- To help MS in their reflections/ policy developments concerning national plans and strategies for RD
 - Specifically in addressing the organisation of healthcare pathways and national and European level
 - Potentially helpful to the Cross Border Health Care Directive Committee in the context of the development of ERNs

Mission and Scope of CEs

- Definition
 - CEs tackle diseases or conditions requiring specific care due to difficulty in establishing diagnosis, to prevent complications and/ or to set up treatments
 - CEs are expert structures for the management and care of RD patients in a defined catchment area, preferably national and at international level if necessary

Mission and scope

- Coverage

- The combined scope of all CEs within a MS covers all RD patients' needs even if they cannot provide a full range of services with the same level of expertise for each RD
- The scope of diseases covered by each CE, or by a CE at a national level, will vary depending on the size of the country and the structure of the health care system
- CEs liaise with other CEs at National or European level as appropriate
- A national directory of formally designated CEs is compiled and made publically available, including on Orphanet

Mission and scope

- Patient focused
 - CEs collaborate with patient organisations to bring in the patients' perspective
 - CEs respond to the needs of patients from different cultures and ethnic groups (ie have cultural sensitivity)
 - According to national/ international ethical and legal frameworks, centres of expertise should ensure respect of non-discrimination and non-stigmatisation of RD patients across Europe, within their sphere of competencies

Mission and scope

- **Competencies**

- CEs bring together or co-ordinate within the specialised healthcare sector multidisciplinary competencies/ skills including paramedical skills and social services in order to serve the specific medical, rehabilitation and palliative needs of RD patients
- CEs contribute to building healthcare pathways from primary care
- CEs have links with specialised laboratories and other facilities

Mission and scope

- Spreading of information
 - CEs contribute to the elaboration of good practice guidelines and to their dissemination
 - CEs provide education and training to healthcare professionals from all disciplines, including paramedical specialists and of non-healthcare professionals (such as school teachers, personal/ homecare facilitators) whenever possible
 - CEs contribute to and provide accessible information adapted to the specific needs of the patients and their families in collaboration with the POs and with Orphanet

Mission and scope

- Research
 - CEs contribute to research, to improve the understanding of disease and to optimise diagnosis, care and treatment, including the clinical evaluation of long term effects of new treatments

Mission and scope covers:

- Definition
- Coverage
- Patient focus
- Core competencies
- Role in spreading information and education
- Role in research

Criteria for designation

- Leadership and credibility
 - High level of expertise and experience documented for example by the annual volume of referrals and second opinions, and through peer reviewed publications, grants, positions, teaching and training activities
 - Contribution to state of the art research

Criteria for designation

- **Multidisciplinarity and inclusiveness**
 - Demonstration of a multidisciplinary approach when appropriate, integrating medical, paramedical, psychological and social needs (eg RD board)
 - Appropriate capacity to manage RD patients and provide appropriate advice
 - Organisation of collaborations to ensure continuity of care
 - Between childhood, adolescence and adulthood
 - Between all stages of the disease

Criteria for designation

- Capacity
 - Appropriate arrangements to improve the delivery of care and especially to shorten the time taken to reach a diagnosis
 - Capacity to produce and adhere to good practice guidelines for diagnosis and care
 - Capacity to propose quality of care indicators in their area and implement outcome measures including patient satisfaction

Criteria for designation

- Capacity continued
 - Capacity to participate in data collection for clinical research and public health purposes
 - Capacity to participate in clinical trials, if applicable
 - Quality management in place to assure quality of care, including national and European legal provisions, and participation in internal and external quality schemes when applicable
 - Consideration of E-Health solutions

Criteria for designation

- Links and collaborations
 - Links and collaborations with patient organisations where they exist
 - Links and collaborations with other CE at national, European and international level
 - Appropriate arrangements for referrals within individual MS from/ to other EU countries where applicable

Criteria for designation

- Mechanisms will need to be in place to capture measures of
 - Leadership and credibility
 - Capacity and quality assurance
 - Appropriate links and collaborations

Process for designation

- Core principles
 - MS take action concerning the establishment and designation and evaluation of CEs and facilitate access to these centres
 - MS establish a procedure to define and approve designation criteria and a transparent designation and evaluation process
 - The designation process at MS level ensures that the designated CEs have the capacity and the resources to fulfill the obligations of designation

Process for designation

- Designation criteria
 - The designation criteria defined by MS are adapted to the characteristics of the diseases or groups of diseases covered by the CE
 - CEs may not fulfill some of the designation criteria defined by the MS so long as the absence of fulfillment of these criteria does not impact on the quality of care and as long as CEs have a strategy in place to attain designation criteria in a defined time period

Process for designation

- Duration of designation
 - The designation of a CE is valid for a defined period of time
 - CE are re-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 CE 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

Process for designation

- MS responsible for designation process based on recommended criteria but adapted according to the MS
- Designation is for a defined duration and subject to quality based review

The European dimension of CEs

- MS with established CEs share their experience and quality indicators with other MS and co-ordinate their efforts to identify CEs for all RD patients at EU level
- This is an important principle but requires the co-operation of national accrediting and quality assurance bodies

The European dimension of CEs

- MS should provide adequate information to professionals , citizens and POs concerning the possibilities and conditions of access to health care at national and international level in the field of RD
- Cross border health care is organised where appropriate with designated CEs in neighbouring or other countries where patients or biological samples can be referred

The European dimension of CEs

- Networking of CEs is a key element of their contribution to patient diagnosis and care, to ensure that expertise travels rather than patients where appropriate; exchange of data, biological samples, radiological images, other diagnostic materials and e-tools for tele expertise are promoted
- Designated CEs at MS level are the key elements of the future ERNs