



D E C L A R A T I O N

Declaration of Common Principles on Centres of Expertise and European Reference Networks for Rare Diseases



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<p style="text-align: center;">Declaration of Common Principles on Centres of Expertise and European Reference Networks for Rare Diseases</p>
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In 2008, EURORDIS adopted this Declaration of “Common Principles on Centres of Expertise and European Reference Networks for Rare Diseases”, in order to improve patient care throughout Europe.

Rare disease patients call upon National Health Authorities to endorse, publicise and implement the following Declaration to contribute to the identification of Centres of Expertise and to support them financially.

Rare diseases are often complex diseases

1. Centres of Expertise shall aim at providing a multi-disciplinary approach^{(1) (2)}
2. Centres of Expertise shall aim at providing patient centred-care. Multidisciplinarity shall be managed in a coordinated manner⁽³⁾, and shall not result in disconnected medical services
3. Centres of Expertise shall represent a reliable source of accurate diagnosis, and shall include genetic testing and genetic counselling
4. Centres of Expertise shall share their competences at both national and European levels⁽⁴⁾ and shall endeavour to constantly increase and update their level of expertise
5. Centres of Expertise should join in European Reference Networks for Rare Diseases.

Rare disease patients are too often excluded from health systems and socially marginalised, in spite of their tenacious personal commitment^{(5) (6)}

6. Centres of Expertise shall be places where patients feel welcome and safe⁽⁷⁾ and where patients are received by knowledgeable and understanding professionals
7. Centres of Expertise shall facilitate and improve the autonomy of the patient
8. Centres of Expertise shall provide access⁽⁸⁾ to social assistance⁽⁹⁾, which respond to the special needs of the disease⁽¹⁰⁾

Centres of Expertise shall not only be “care giving structures”, but shall also engage in the following activities:

9. Centres of Expertise and European Reference Networks shall actively involve patients and their representatives in the establishment and performance, management and evaluation of the centre ⁽¹¹⁾. These evaluations should be made publicly available
10. Centres of Expertise shall exchange information with local professionals⁽¹²⁾, including general practitioners ⁽¹³⁾
11. Centres of Expertise and European Reference Networks shall disseminate information on the diseases to social and other relevant stakeholders involved ⁽¹⁴⁾
12. Centres of Expertise shall provide training ⁽¹⁵⁾ to all stakeholders involved, including health care professionals, patients and their representatives
13. Centres of Expertise and European Reference Networks shall provide guidelines on the most appropriate care management for patients, closely integrating both medical and social aspects. They should involve patients and give them an active role as recognised partners at all stages.
14. Centres of Expertise and European Reference Networks shall facilitate the coordination of both basic and clinical research activities and infrastructures, including clinical trials, registries, biobanks, exploration of innovative techniques, etc. They should also be required to publish and disseminate research results, irrespective of whether the results are positive or negative
15. Access to Centres of Expertise must be ensured to all patients, regardless of their country or region of origin

The following figures are based on the **EurodisCare3 Survey** on access to health services, for which a total of 5995 responses were received from 22 countries for 16 diseases, thanks to the active involvement of 130 patient organisations.

- (1) Each patient went through an average of four different types of medical consultation, three kinds of examination and 2.4 types of treatment over the last two years, in relation to his/her disease.
- (2) During the same period, almost half of these (47%) spent time in hospital for an average of three times for 20 days in total.
- (3) 94% of patients consider that “coordinating the sharing of medical information on the patient between all professionals who care for him/her in the specialised centre” is essential (70%) or useful (24%).
- (4) 95% of patients consider that “communicating with other specialised centres and professional networks to harmonise treatments and research at the national and European level” is essential (67%) or useful (28%).
- (5) An average of 59% of the respondents (up to 64% for the low income group) had to reduce or stop their professional activity because of their disease or to take care of a relative affected by a rare disease.
- (6) On average, 16% of patients (up to 24% for the low income group) were forced to move house because of their disease.
- (7) One out of 5 patients (18%) experienced rejection linked to their disease from healthcare professionals. The patient perceived reason of rejection is linked to the disease (80% of cases due to reluctance because of the complexity of the disease), and/or to the physical conditions of the patient: 10% for disease-related behaviour, 11%, for communication difficulties and 15% for physical aspect.
- (8) Every year, 28% of the patients needed the assistance of a social worker. For about one-quarter of these, access to this assistance was difficult: difficult access (18%), very difficult (9%) or even impossible (4%).
- (9) 92% of patients consider that “informing patients about their rights and guiding them toward social services, schools, leisure activities or vocational guidance” is essential (55%) or useful (37%).
- (10) Globally, social assistance services respond inadequately to the expectations and needs of rare diseases patients (only 37% of patients are satisfied), especially when the demands are specific to the disease: 27% for assistance to obtain exceptional financial support, such as the purchase of a wheel chair, 32% for assistance with social integration, school, leisure or professional integration. This inadequacy of the social assistance is more severe for the low income patients (only 26% of satisfied).
- (11) 96% of patients agree that “a specialised centre should involve patient organisations in order to benefit from their knowledge of daily life and needs of patients”.
- (12) 90% of patients consider that “creating material for teachers, employers, social services, insurance companies and the general public to inform them about patients’ needs and improve social integration of patients” is useful or essential
- (13) 44% of patients disagree that “the role of general practitioners consists mainly in looking after health problems not related to the rare disease”.
- (14) 95% of patients consider that “coordinating the sharing of medical information between health professionals of the specialised centre and local health professionals” is useful or essential.
- (15) 93% of patients consider that “training local professionals to respond to the specific needs of patients” is useful or essential.