EURORDIS
Rare Diseases Europe

National Workshop reports

Question 3:
Cooperation with other countries and recommendations for European reference networks

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How do you see your centres cooperating at the EU level?

- **Elements to establish European cooperation:**
  - **National/regional networks of specialised care centres/centres of reference (G, I)**
  - **Already established networks (Cz, F, UK)**
  - **Patient hosted networks and voluntary activity (UK)**
  - **Specialised health care professionals(LUX)**
  - **Fora like meetings/conferences(Nl,UK,Sw)**
  - **Websites/information,databases/registries(UK,F,Dk, I,P,Sp)**

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How do you see your centres cooperating at the EU Level

- **Remarks and recommendations:**

- **Expert teams for very rare diseases/different approach needed (F, Dk, Sp)**
- **Holistic approach (social aspects/quality of life) (F, Dk, Cz)**
- **Reimbursement systems to be adapted (I, Sp, F, Sw)**
- **Interaction with stakeholders including patients' org. (Dk, P)**
- **European research projects to be developed to networks (F, P, LUX)**
- **Risk of creation of a disproportionate bureaucracy relative to numbers of patients (UK)**

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What role would play European reference networks?

- Improve knowledge by sharing information/databases (Dk, Cz, Nl, P, F,UK)
- Establish research projects, studies, trials(increase cohorts) and develop registries and databases (P, Sp, Dk, I, G, F, Sw)
- Develop best practices / protocols (P, Cz, Dk, Sw, F, Sp, G, I)
- Grouping disorders (UK, I)
- Defining quality / recommendations for care services/ standard of care (Nl, P, F, UK)

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What role would play European reference networks?

- **Remarks and recommendations:**

- **Expertise should “travel” to the patients, but it should be possible for patients to travel to centres if necessary (P, Dk)**
- **Accrediting national centres of expertise (recognised centres of expertise) / list of centres(UK, Sp)**

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Which specific added value can you identify when your national centres of expertise belongs to a European network?

- **Creation of the critical mass for research and clinical trials (G, Sw, F, P, Cz, UK, Sp)**
- **Shared databases and registries (F, Cz, Dk, LUX, Sp)**
- **Creation of a multidisciplinary approach (I,F)**
- **Pool knowledge for protocols and state of the art treatment (I, Nl,P, Cz, LUX, UK, Sp)**

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Which specific added value can you identify when your national centres of expertise belongs to a European network?

- **Remarks and recommendations:**

- **Long term resources/funding needed, as it takes at least 10-15 years to build a register (F)**
- **Improvement of care and services on national level when benchmarking on European level (UK, G, P, F, Cz, Dk)**
- **Uniform approach might better integrate rare patients in the healthy population (Cz)**
- **Support network for travellers (Cz, F)**
- **For very rare diseases substitute a missing national centre (Cz)**

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On which criteria to identify/designate European reference networks?

- **Flexible criteria pending on complexity, rarity and the development in the single country (F, Cz, Dk)**
- **Clear objectives and visions for each network (Sw, Dk)**
- **Ability to share information and to benchmark (disclose procedures and results) (G, Sw, Cz)**
- **Groups of disorders rather than single diseases (I, UK)**
- **Minimum standards and common procedures (Dk)**
- **Same criteria as national centres of expertise (G, P, Nl)**
- **Quality of care, number of patients, publications issued (Sp)**

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On which criteria to identify/designate European reference networks?

- **Remarks and recommendations:**

”Leading” centres and ”associate centres” should be identified on the basis of acquired and proved experience (I)

- **Clear leadership needed (Sw)**
- **Each member state should identify its experts for rare diseases (F)**
- **Some networks regulate themselves (EuroWilson) (F)**
- **Creation of a European monitoring body (F)**
- **Credits should be allocated to criteria e.g. effective cooperation (F)**

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What would the expected specific benefits for patients be?

- **Improved quality of information, care and services (Sp, Lux, UK, CH, F, P, I)**
- **Earlier diagnosis and recognition of the importance (Sp, Lux)**
- **Creation of multi- diciplinary teams (UK)**
- **Harmonisation and standardisation of best practices / guidelines (Sp, Lux, Cz, P, Sw, I)**
- **Access to the best European resources for rare diseases (Cz)**
- **Better incentives for research by pooling patients / registries (Sp, Lux, Cz, Sw, I)**
- **Recognition of rare diseases and thus of their specific features as regards care (F)**
- **Less peregrination (Sp)**

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What would the expected specific benefits for the patients be?

- **Remarks and recommendations?**

- **Opportunity for a second opinion (I)**
- **Improved quality of life (Lux, Nl, Cz)**
- **Better access to care in the poorest countries (F)**
- **Contacts between patients on the European level (Cz, Nl)**
- **Reimbursable care when travel in Europe (F)**
- **Progress by comparison of systems and cultures (F, Dk)**
- **Better access to Orphan Drugs (Sw)**

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Complementary aspects

How do you see your centres cooperating at the EU level?

- **Elements to establish European cooperation:**
  - **EU networks basis for experts and expertise to travel to the patient (UK, Sw)**
  - **Equal access for patients to services from EU Networks (G, Dk)**
  - **Long term funding needed (F)**

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What role would play European reference networks?

- **Training, exchanging resources, twinning between centres (Cz, Dk, Sp, I, P, Sw)**
- **Encourage networks between patients (Nl) educating patients and families (P)**

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Which specific added value can you identify when your national centres of expertise belongs to a European network?

- **Training of professionals (Sw, P, Cz, Dk, Lux)**
- **Better surveillance on medicines concerning efficacy and safety (I)**
- **Creation of a greater and better link between health care professionals and patients (UK)**

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On which criteria to identify/designate European reference networks?

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