EUROPEAN REFERENCE NETWORKS
PATIENTS’ PERSPECTIVE

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Presentation overview

- Background to EPF
- EPF and cross border healthcare – the role of patient organisations - Strong cooperation with EURORDIS-leadership on ERNs
- European Reference Networks
  - Our Vision
  - Patient Involvement - Critical Success Factor
  - Key priorities
- Conclusions
About the European Patients’ Forum

• Independent, non-governmental umbrella organisation set up in 2003

• **VISION:** All patients in the EU have equitable access to high quality, patient-centred health and social care

• **MISSION:** To ensure that the patient community drives health policies and programmes

• **MEMBERS:** disease-specific EU & national coalitions – 64 member organisations"
Cross-Border Directive

- EPF/ EURORDIS Instrumental
- Overall “verdict”

Important Codification of Rights

Wider Policy Issues

Some specific areas of concern:

- Quality and safety – will the CBD deliver safe, high quality healthcare?
- Equity – is cross-border healthcare an option for all?
- Information to patients & citizens – what do patients want to know?
EPF Regional Conferences

Meaningful Patient Involvement

• 4 Regional Conferences on Cross Border Healthcare
  – Brussels, Athens, Ljubljana, Tallinn

• Core group to encourage the implementation of the Directive, information to peers, guidance to NCPs

• Informal network - evaluate implementation in each country and support authorities to overcome eventual bottlenecks.

• Conference in Brussels planned for June 2015, NCPs and patient leaders on the eve of the Commission’s report to Council
Patient involvement

- Patient organisations= wealth of unique expertise and experience that can help develop better services for patients. We are committed to sharing this expertise.
- Involving patients in all aspects of implementation of CBD: a pre-requisite – to ensure that policies and practice are fit for purpose and patients really benefit, at the end of the day.

*Similar compelling rationale for patient involvement in ERNs........*
“The main added value of the European Reference Networks and of the Centres of Expertise is the improvement of access to both diagnosis and high-quality, accessible and cost-effective healthcare for patients who have a medical condition requiring a particular concentration of expertise or resources, particularly in medical domains where expertise is rare”

Summary report of the replies on the PUBLIC CONSULTATION ON THE IMPLEMENTATION OF EUROPEAN REFERENCE NETWORKS (ERN), European Commission
European Reference Networks for RDs

- There are over 6000 diseases which are rare.
- The challenges of rarity:
  - Patients are rare + experts & expertise are rare.

- CoE pinpoints expertise and gathers existing experience to improve patient care.
- To organise the healthcare pathways at national and EU levels, networks are key.
- CoE can have very different structures → ERNs need to be flexible to integrate these differences.
Core tools & activities

1. **Disease registries**: international terminology to support interoperability as part of global data-sharing effort.

2. ERNs should promote the use of lab testing facilities which participate in **Quality assurance programmes** (EuroGentest)

3. ERNs should develop a mechanism for **sharing good practice guidelines** for diagnosis and care between MSs

4. **Training and education tools** to raise standards of care

5. **Evaluation of ERNs**: multi-stakeholder (incl. POs) with indicators covering processes, outcomes and impact (PROs)
Core tools & activities

- **Communications infrastructure** to ensure visibility and transparency of ERNs, their processes & accessibility (own website & Orphanet)

- **Cross-border referral** mechanisms to help operate the CBHC & Reg. on the coordination of SSS

- In all of these areas, **eHealth and Telemedicine** are core to support tele-consultation, training & education – Findings of Chain of Trust- Patients’ and HCPs’ trust, confidence and acceptance
European Reference Networks

Now, focus on implementation – what should be envisaged at national level (including National Plan):

- how to integrate different structures
- how to find adequate funding
- how to ensure real patient involvement
- how to provide comprehensive care
- how to promote research

Minimum common denominator: a ERN should gather a critical mass of patients to support research and develop best practices.
Patients’ vision

- All RDs covered by at least one ERN which focus on groups of diseases such as rare hematologic diseases, genodermatoses, rare pulmonary diseases, etc.

- ERNs should deliver & disseminate structured healthcare pathways through a high level of integrated expertise to improve diagnosis and care to the best European standards.

- **Future:** 20 to 30 RD ERNs to be established ‘based on the concept of medical specialties and body systems: diagnostic and therapeutic areas can be identified each covering a wide range of rare diseases’
Rare disease patients’ vision

- RD ERNs must be **multidisciplinary** to address multisystem disorders and include social care: network between Centre of Expertise, healthcare providers, social workers, patient organisations, genetic testing labs, research groups...
Patient involvement – we said..

- Patient representatives involved in the management of a ERN in a meaningful way – membership of steering committees/Board/project groups.
- Patient groups should be involved at all levels of activity, including governance and evaluation.
- ERN should promote networking of the patient groups representing the conditions covered (→ Federation).
- Participation of patient organisations should be a prerequisite for an ERN to receive funding.
- Budget of the ERNs should include funding for patient organisations to allow full participation.
ERN Criteria

Commission Delegated Decision

• Horizontal, structural criteria –
  – Patient centredness ,
  – patient empowerment
  – *Meaningful* Informed consent (cf. CTR)

• BUT........absence of explicit reference to patient involvement
EUCERD Recommendations

• Patient involvement critical and should be integral in governance structures and evaluation

• Inclusion in technical guidance and manual that will be produced to support implementation

• Absolutely vital that PO involved in accreditation and designation of CoE, ERN

• Transparency – positive and negative assessments
Rome was not built in a day

- Implementation will be stepwise and progressive, starting from the most advanced & organised groups;

- Better to identify short, medium and long term priorities and do them well rather than try to do everything at once;

- Patients’ priorities include:
  - Best practice guidelines for diagnostics and care
  - Networking between HCPs & patient groups
  - Clinical research, registries, clinical trials
  - Social care
Conclusions

• Patients Organisations and our members – fundamental in driving the legislation forward – equally vital for effective implementation

• Valued as equal partners - unique expertise, experience, no room for tokenism

• EPF and EURORDIS and our constituencies- strong track record of effective collaborative work

• EURED meeting in July – important opportunity to navigate a way forward
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