

EUROPEAN REFERENCE NETWORKS PATIENTS' PERSPECTIVE

Nicola Bedlington

23 June 2014

Brussels

“ A STRONG PATIENTS' VOICE TO
DRIVE BETTER HEALTH IN EUROPE ”

- 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

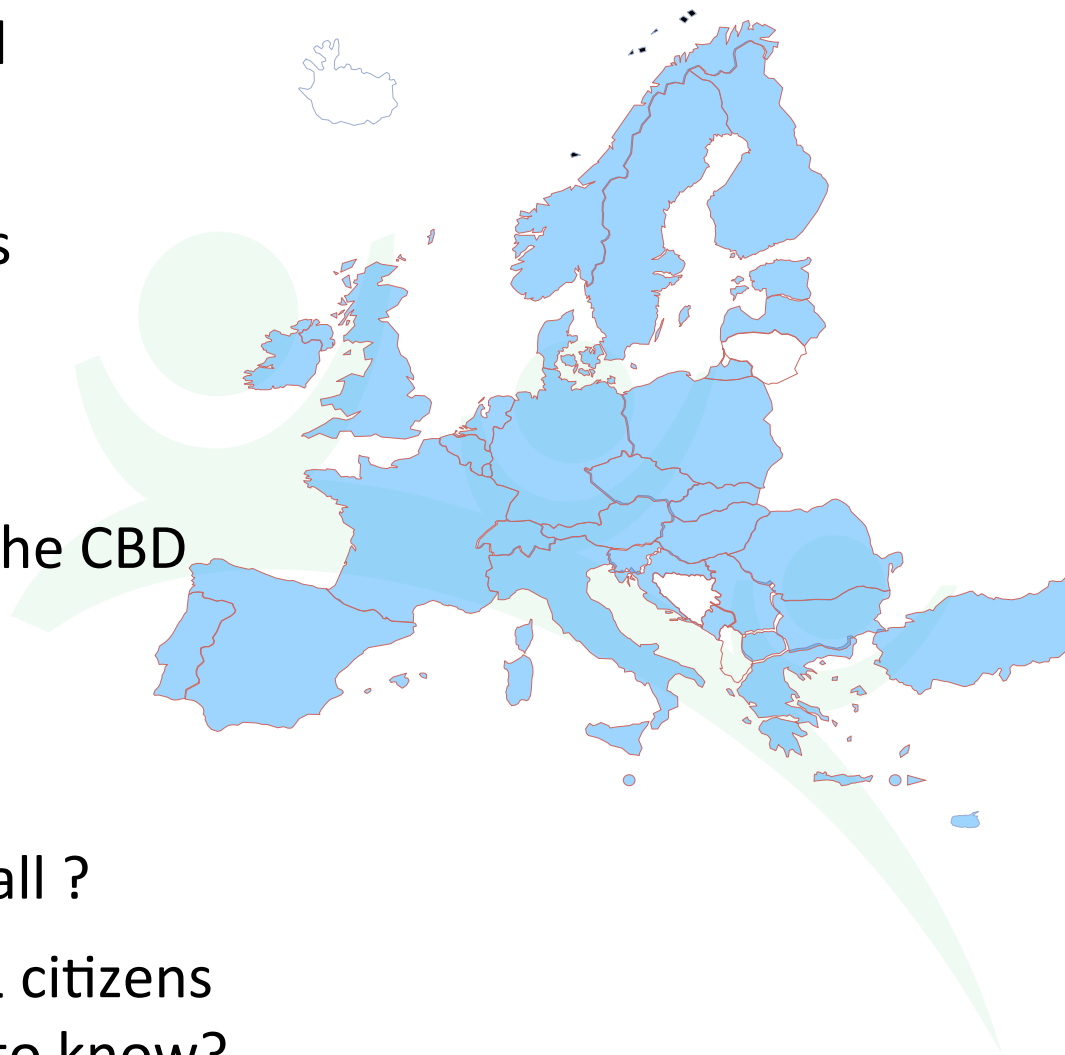
- EPF/ EURORDIS Instrumental
- overall “verdict”

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?



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.

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

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.

- **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.

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
- EUCRED meeting in July – **important opportunity to navigate a way forward**

THANK YOU TO EURORDIS!



www.eurordis.org

THANK YOU FOR YOUR ATTENTION!

Follow us on Social Media!



/europeanpatientsforum



/eupatient



/eupatientsforum



eu-patient.eu/blog

More information

www.eu-patient.eu

info@eu-patient.eu

“ A STRONG PATIENTS' VOICE TO
DRIVE BETTER HEALTH IN EUROPE ”