

# A Proposed European Reference Network For Rare Congenital Malformations And Intellectual Disability

Coordinated By Jill Clayton-Smith

# The Principle Of ERNs; Third Health Programme

## Specific Objective 4

- To facilitate access to better and safer healthcare for EU citizens, including cross border healthcare
- To increase access to medical expertise and information for rare conditions
- To facilitate application of results of research
- To develop tools for the improvement of healthcare quality and patient safety

# Call for European Reference Networks issued 16.3.16

- Broad overarching networks, as defined by EUCERD
- At least 10 members from at least 8 member states but no official limit.  
APPLICANTS ARE HEALTH CARE PROVIDERS
- HCPs must be endorsed as experts in the field by their Member States
- Affiliate members/second wave members come later
- The initial application is for a **Framework Partnership Agreement**, for 5 years , simultaneously submit grant application for first year
- Application for funding will be one year at a time thereafter, maximum of 200,000 Euros/year. 40% co-funding

# Proposed Operational Criteria Of An ERN

The following table summarises the themes covered in the Operational Criteria for the Network and Healthcare Providers.

Themes in the Operational Criteria		
	Network	Healthcare Providers
Themes	<ul style="list-style-type: none"> <li>• Establishment of a European Reference Network</li> <li>• Highly Specialised Healthcare</li> <li>• Governance and Coordination</li> <li>• Patient Care</li> <li>• Multidisciplinary Approach</li> <li>• Good Practice, Outcome Measures, and Quality Control</li> <li>• Contribution to Research</li> <li>• Continuous Education, Training, and Development</li> <li>• Networking and Collaboration</li> </ul>	<p><b>General Criteria:</b></p> <ul style="list-style-type: none"> <li>• Patient Empowerment and Patient-Centred Care</li> <li>• Organisation, Management, and Business Continuity</li> <li>• Research, Education and Training</li> <li>• Expertise, Information Systems, and e-Health Tools</li> <li>• Quality and Safety</li> </ul> <p><b>Specific Criteria:</b></p> <ul style="list-style-type: none"> <li>• Competence, Experience and Outcomes of Care</li> <li>• Human Resources</li> <li>• Organisation of Patient Care</li> <li>• Facilities and Equipment</li> </ul>
Assessment	Each criterion is rated <u>once</u> for the overall Network.	Each criterion is rated <u>individually</u> for each Healthcare Provider within the Network.

# A Proposed ERN For Rare Congenital Malformations and Intellectual Disability

We seek to provide a patient centred network which will meet the needs of those with rare congenital malformation and intellectual disability syndromes , both diagnosed and undiagnosed and will provide an infrastructure for diagnosis, evidence-based management and collection of patient data. The network will add value to existing services, disseminate best practice guidelines to optimise patient care, facilitate training and capacity building in field, inform the work of service commissioners and enhance research and development of future therapies.

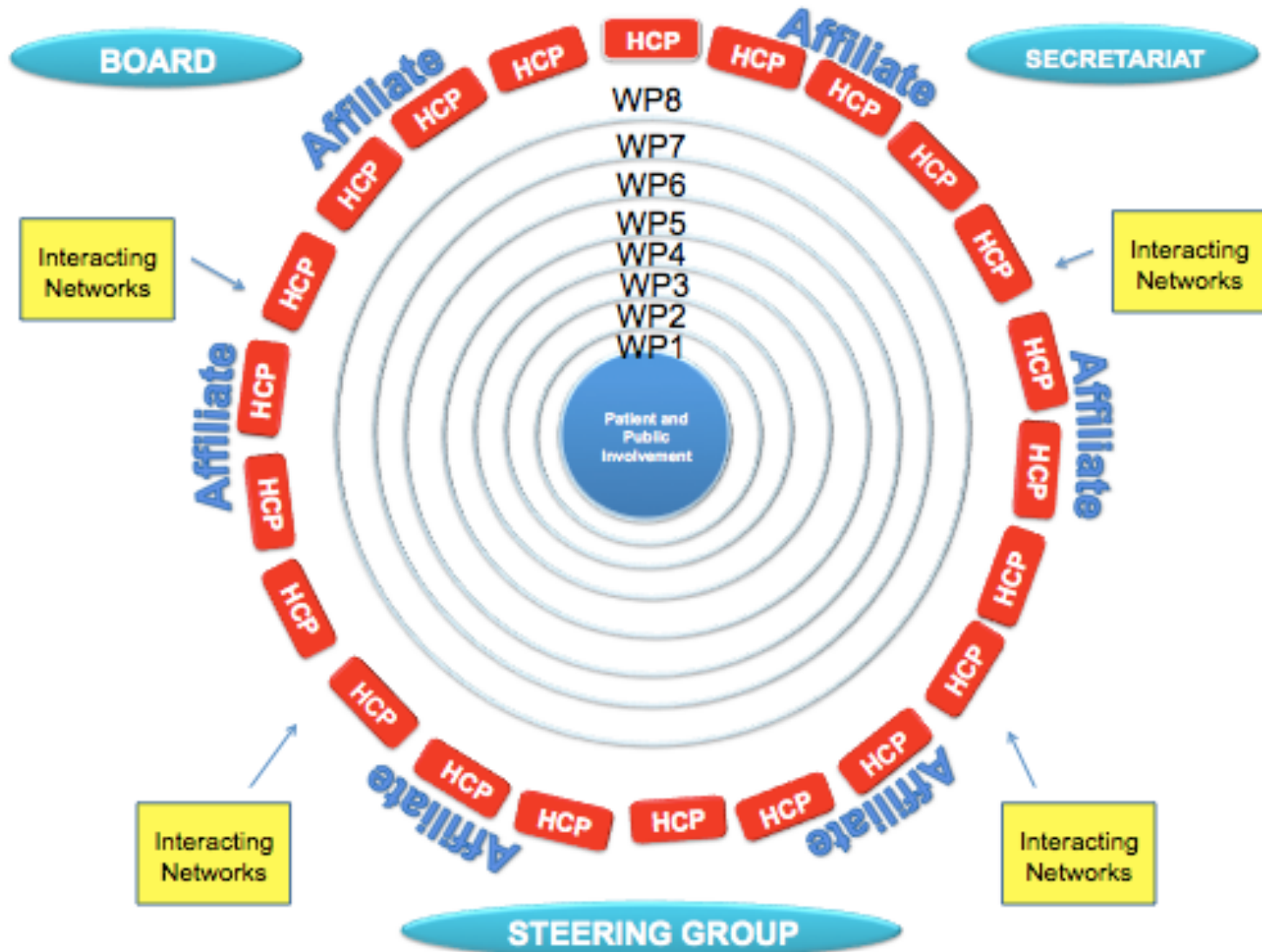
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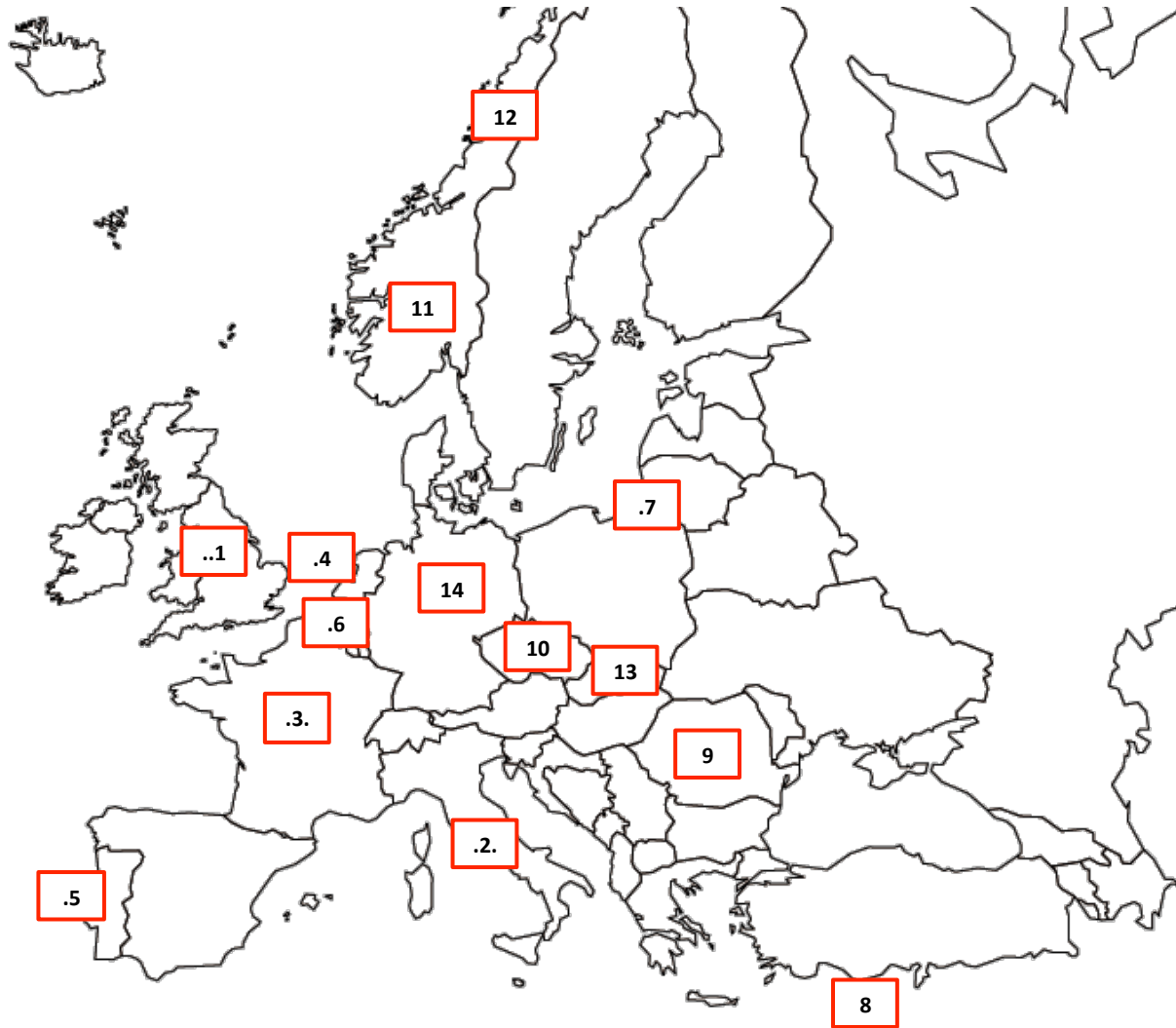
## ITHACA

Intellectual disability TeleHealth And Congenital Anomalies

# Proposed ERN Structure



# ITHACA ; RARE CONGENITAL MALFORMATIONS AND INTELLECTUAL DISABILITY



Endorsement process is on track in:

- 1.UK
- 2.Italy (may be more )
- 3.France (June 17<sup>th</sup>)
- 4.Netherlands
- 5.Portugal
- 6.Belgium
- 7.Lithuania
- 8.Cyprus
- 9.Romania
- 10.Czech Republic
- 11.Sweden
- 12Finland
- 13 Hungary
- 14 German ( still in progress)



# Patient Involvement

An overarching feature of our network  
Initiated from the beginning  
Patient/lay group workshop convened  
EURORDIS election of e-PAG representatives  
Teleconferences for patient/lay groups  
Inclusion in workpackage development  
Suggestions for how we can work together



# Workpackages

Management and Coordination  
Dissemination  
Evaluation

Expert patient care  
TeleHealth and Diagnosis  
Patient Registries  
Research  
Teaching and Training

Required to identify goals, objectives and deliverables,  
methods to deliver and the timeline for this

# Challenges

- Determining membership
- Setting up a network with no initial resources
- Communication and IT
- Large amount of EU paperwork (3 docs/HCP plus additional 4)
- Avoiding overlap with other networks and initiatives
- Choosing SMART deliverables which are achievable within our likely budget
- Writing a competitive application – not all proposed networks will be funded

# The Positives So Far

- Even before a network is approved, parents and professionals have spent many hours of time thinking how they can improve the lives of those with rare disease
- We have learned a huge amount from patients about what they want and what they can contribute
- We have learned a great deal from each other

# Current Position

- 38 possible members from 15 member states
  - Good patient Involvement
  - Central review of HCP Self Assessments
  - 5 year plan completed
  - IT plans ongoing
  - Challenge of submission process ahead!
- UK 2
  - FRANCE 8
  - NETHERLANDS 4-5
  - ITALY 7-9
  - GERMANY 2-3
  - BELGIUM 3
  - ROMANIA 1-2
  - HUNGARY 1
  - CZECH REPUBLIC 1
  - PORTUGAL 1
  - LITHUANIA 1
  - CYPRUS 1
  - SWEDEN 1
  - FINLAND 1
  - (SPAIN)