



EQUITABLE ACCESS FOR ALL PERSONS WITH RARE DISEASE

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Session 0605, Theme 6: Global Rare Equity: Are
we there yet? Vienna

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EURORDIS.ORG

Introduction

RARE Diseases



Rare Diseases Community:

- Our world is small
- Rare Diseases do not see borders
- Critical mass is need with a common goal
- Our ambition and vision is bold, but realistic and possible
- Recognition that rarity calls for increased international cooperation and mobility of experts
- Digital age is evolving, changing how we live, work and interact.

ERN Spearhead EU Expertise



Networks harness the collective knowledge and experience of experts, focusing on a common goal to drive **improve access to diagnosis and treatment** by providing high-quality healthcare to patients.

- Connect expert, anchored into national health systems
- Creating a critical mass of cases and data
- Inclusive, not exclusive, multi-professional, not single professional
- Common language, common platform enabling mobility of expertise
- Collaborative spirit, trust and sharing with a common goal
- Culture of learning
- Increase patient outcomes and survival

ERN Stage of Development



ERN Implementation
(2015/17)

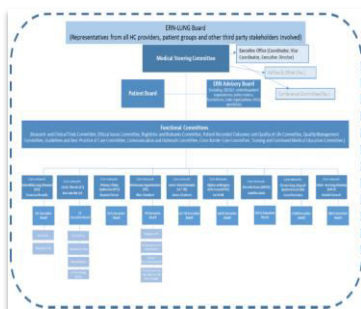


ERN Deployment (2018/20)



ERN Consolidation
(2020/22)

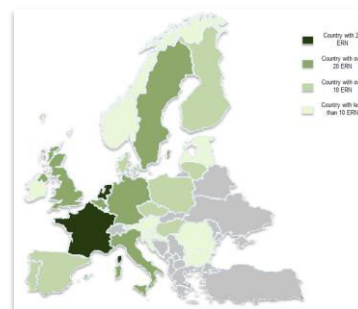
ERNs Deployment (2018-2020): Building Infrastructure & Interoperability



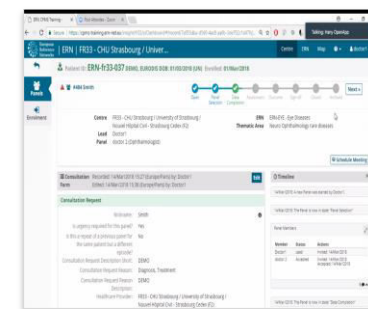
Network Governance & Core Networks



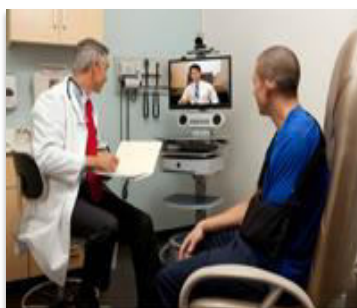
Building interoperability



Expanding Membership



EC IT Platform (CPMS) and Registries



100 Case Panels



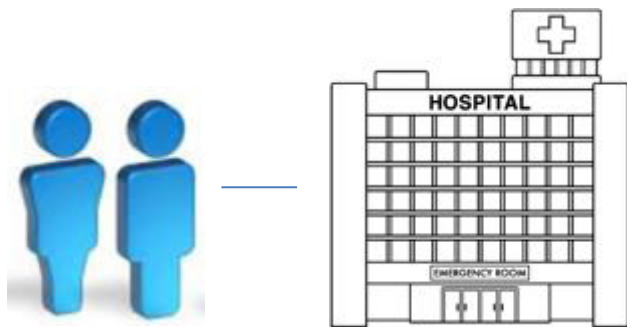
Performance Monitoring



Mapping activities, expertise and resources

Access Expertise

ERN is more than the sum of its parts → collective brain of network, drawing on the experiences and knowledge of all members, to direct care locally



Patients

National Healthcare
Provider



European
Reference
Networks

RD Specific ERN

- **Virtual healthcare:** specialist advice
- **Knowledge generation:** sharing experience and expertise, research and innovation
- **Knowledge dissemination:** clinical guidelines, healthcare pathways, education and training



ERN International Collaboration

Collaborate



- Exchange knowledge and best practices
- Sharing networking experiences to improve networks capacities

Connect



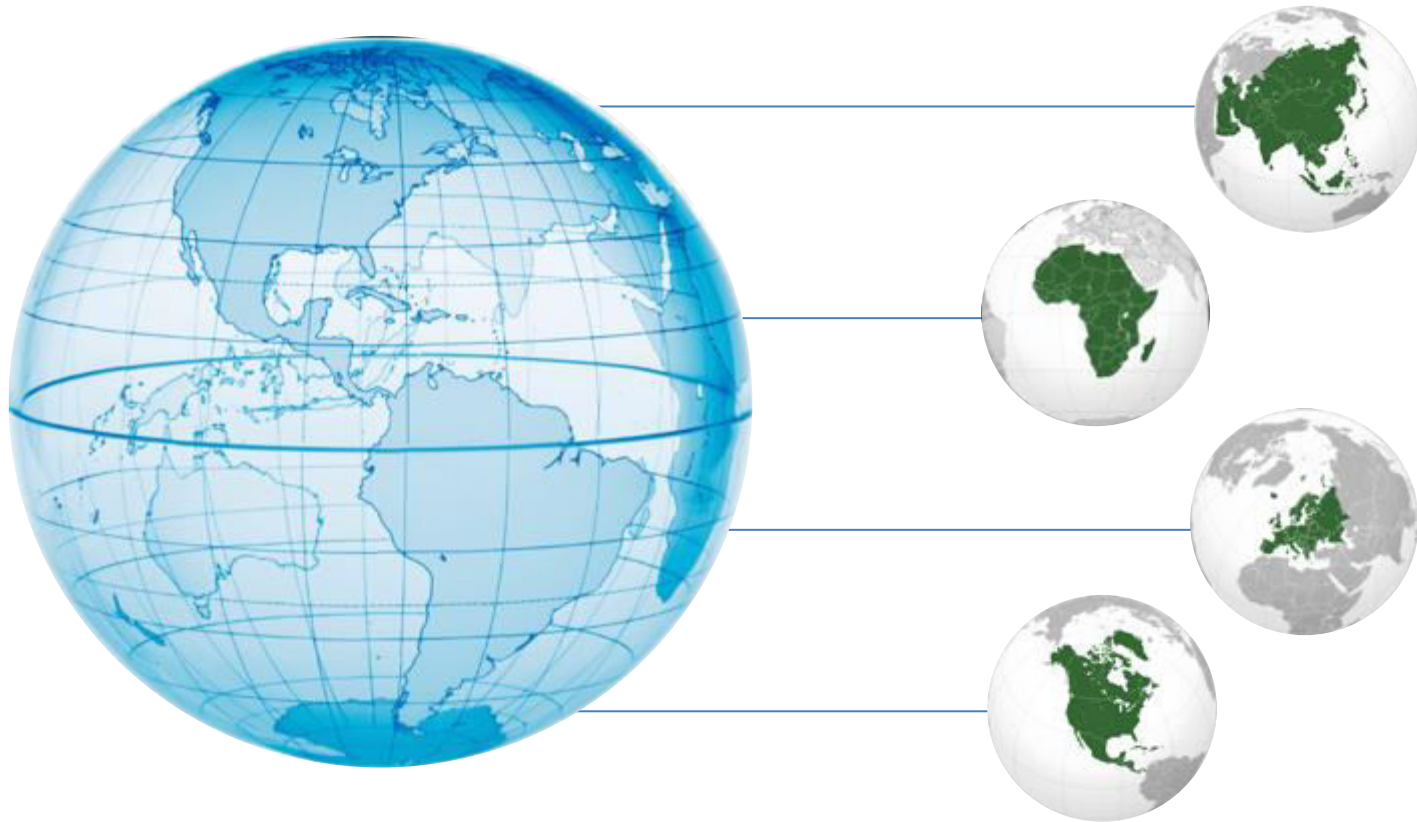
- Healthcare
- Clinical guidelines
- Medical Training
- Research and Clinical trials
- Registering data in common registries

Communicate



- Development of clinical guidelines
- Clinical information
- Models of operation
- Coordination practices
- Training and education

International Network Model



**International Reference
Network**

+



**Regional Centres of
Expertise**

Our Global Opportunity

Ambitious Goal n°2:

- Strengthen healthcare systems and promote universal health coverage
- Improving access to accurate diagnosis, prevention of co-morbidity and multi-disciplinary holistic care

Our Five Point Plan:



Policy & Governance



Accreditation Framework



Network Membership Conditions



Digital technologies to enable collaboration and sharing



Expanding Healthcare Pathways & Guidelines

Degree of Feasibility

Rights & Obligations



Technologies

Equity of Access

Thank You ...

