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Health and Food Safety





The ERN

Networks of healthcare providers aiming at improving quality, and safety and access to highly specialised healthcare

Patients affected by rare or low prevalence and complex diseases

Multidisciplinary approach (different specialities/areas of knowledge)

Added value at EU level

European Reference

Networks

Need of cooperation:

- Scarcity knowledge
- Need education
- Complexity / high cost
- Effectiveness in the use of resources

"The knowledge travels, not the patient"











Quality
High specialisation
Expertise
Knowledge
Research
Clinical care



Innovation
Trust
Solidarity
Generosity
Common project
eHealth



The approval process















ERN activities

European Reference Networks



National Member of a ERN

Affiliated partner

Networks

26 COUNTRIES



> 300

HOSPITALS







BOND ERN	Bone diseases
CRANIO	Craniofacial anomalies and ENT disorders
Endo-ERN	Endocrine conditions
EpiCARE	Rare and complex epilepsies
ERKNet	Kidney diseases
ERN GENTURIS	Genetic tumour risk syndromes
ERN-EYE	Eye diseases
ERNICA	Inherited and congenital anomalies
ERN-LUNG	Respiratory diseases
ERN-RND	Neurological diseases
ERN-Skin	Skin disorders
EURACAN	Solid adult cancers

EuroBloodNet	Once hematelegical diseases
Europioodivet	Onco-hematological diseases
EUROGEN	Urogenital diseases
EURO-NMD	Neuromuscular diseases
GUARD-HEART	Diseases of the heart
ITHACA	Congenital malformations and intellectual disability
MetabERN	Hereditary metabolic diseases
PaedCan-ERN	Paediatric cancer
RARE-LIVER	Hepatological diseases
ReCONNET	Connective tissue and musculoskeletal diseases
RITA	Immunodeficiency, auto- inflammatory and auto-immune diseases
TRANSPLANT- CHILD	Transplantation in children
VASCERN	Multisystemic vascular diseases



Share. Care. Cure.



Virtual

Virtual clinical consultations

Remote monitoring and follow-up





ERN e-health/telemedicine tools under development



IT tools

Communication and collaboration platform

Online patient management platform

2017

Knowledge sharing

e-learning

Training

website

Rare disease registries (ERNs, CHAFEA, JRC)

2018

2019...

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What's next?

- ERNs roll out
- Challenges
- Tools development
- New form of collaboration
- Funding schemes
- Next steps





ERNs roll out

- 28 February: start of ERN communication actions
 - Press conference + communication material
- 8 March: BoMS + BOMS & ERN coordinators meeting
 - ERNs priorities and integration into national healthcare systems
- 9 March: ERN Conference
 - Brochure, flyer, video clip + video reportage...
- 10 March: Kick off meetings
 - ERNs start working....







Actors involved in the ERN implementation







Commission expert group on rare diseases



ERNs BoMS







Reference

Networks









Consumers,
Health and Food
Executive Agency



Professional / scientific organisations



Challenges

- Definition of the <u>legal status of ERNs</u>
- Authorisation and reimbursement mechanism
- Integration of ERNs with national healthcare systems
- EU data protection legislation in cross-border care
- Interoperability of IT solutions
- Coordination of ERN <u>relevant funding</u> streams
- Dissemination and communication activities
- Development of <u>European clinical guidelines</u>
- ERN cooperation in relevant frameworks
- <u>Participation of UK HCPs in a post-Brexit</u> scenariot
- <u>Sustainability</u> of ERNs and opportunities for continued funding post-2022





Funding/support









STRUCTURAL FUNDS









Next steps



- End 2017 new call for HCPs to join existing ERNs
- 2019 call for new Networks







Further information:

http://ec.europa.eu/health/ern/policy/index_en.htm

