



European
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Networks

ERN - Europäische Referenznetzwerke in Deutschland

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European Commission

Berlin 13 February 2017



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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

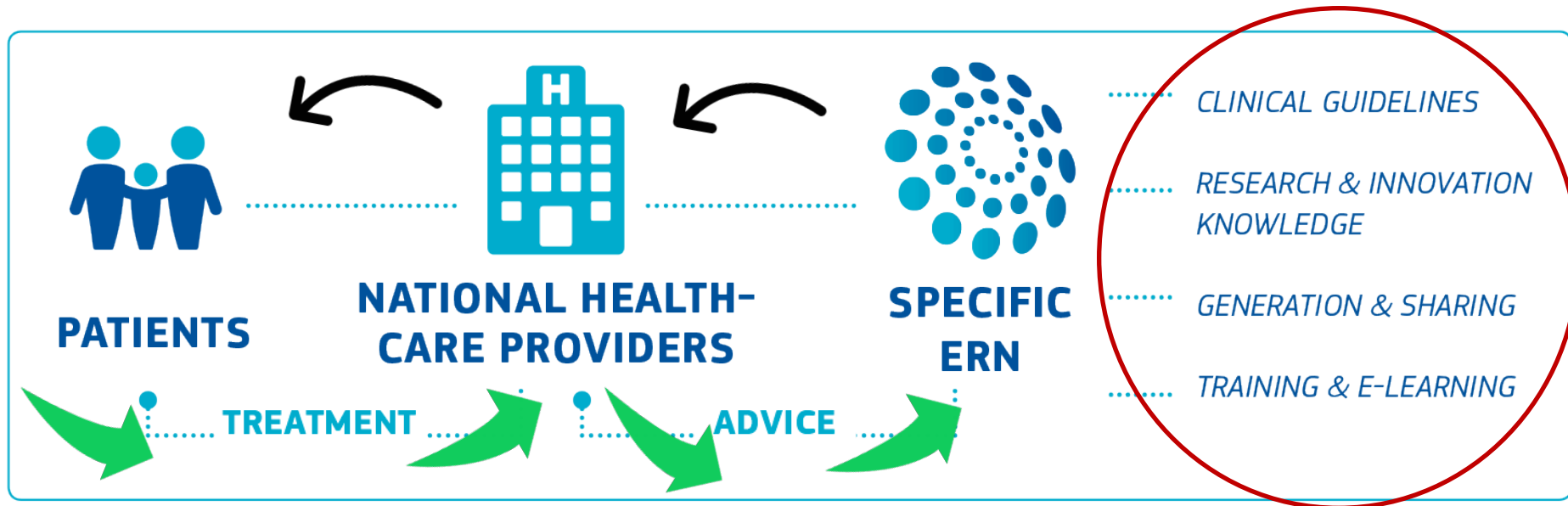
Added value at EU level

Multidisciplinary approach
(different specialities/areas of knowledge)

Need of cooperation:

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

"The knowledge travels, not the patient"



**Clinical
virtual care**

**Remote monitoring &
follow-up**

**Remote guidance and
diagnosis**



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Research, innovation & knowledge generation

Key Elements of ERNs

- A framework for structured cooperation to maximise cross-country expertise through joint research projects and clinical trials
- ERN provide an opportunity to build top level translational and basic research around shared strategies
- Dissemination of research results, education & training activities



Outcome call 2016



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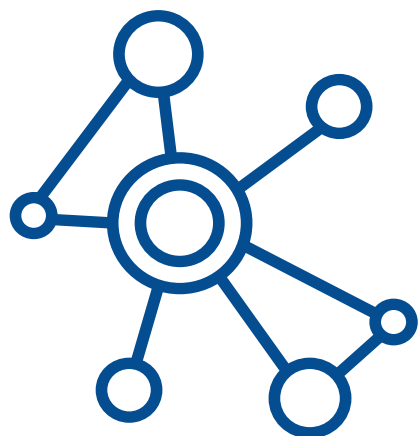


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23 (24)



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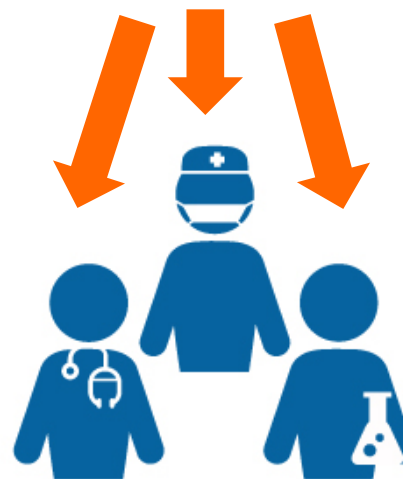
26 COUNTRIES



> 300
HOSPITALS

Full
Member

Affiliated
partner
(late 2017 ?)



> 900
HEALTHCARE UNITS

Health and
Food Safety



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BOND ERN	Bone Diseases	EuroBloodNet	Onco-Hematological Diseases
CRANIO	Craniofacial anomalies and ENT disorders	EUROGEN	Urogenital Diseases
Endo-ERN	Endocrine Conditions	EURO-NMD	Neuromuscular Diseases
EpiCARE	Rare and Complex Epilepsies	GUARD-HEART	Diseases of the Heart
ERKNet	Kidney Diseases	ITHACA	Congenital Malformations and Intellectual Disability
ERN GENTURIS	Genetic Tumour Risk Syndromes	MetabERN	Hereditary metabolic diseases
ERN-EYE	Eye Diseases	PaedCan-ERN	Paediatric Cancer
ERNICA	inherited and congenital anomalies	RARE-LIVER	Hepatological Diseases
ERN-LUNG	Respiratory Diseases	ReCONNET	Connective Tissue and Musculoskeletal Diseases
ERN-RND	Neurological Diseases	RITA	Immunodeficiency, AutoInflammatory and Auto Immune Diseases
ERN-Skin	Skin Disorders	TRANSPLANT-CHILD	Transplantation in Children
EURACAN	Solid Adult Cancers	VASCERN	Multisystemic Vascular Diseases

Phases of the ERN life cycle



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We
are
here

2011-14

Legislation and initial planning

Directive
Implementing decisions
Awareness and communication

2015-16

Implementation: (Approval stage)

Design and development
Assessment tools
Call for ERN
Assessment of Network proposals
Approval of ERNs

2017-18

Implementation: (deployment stage)

Establishment
Initial organizational phase
Functioning (initial actions and services)
Partial service production

2019-20

Consolidation

Full service production
Continuous monitoring
Performance indicators and initial outcome assessment

2021

Evaluation and update

project cycle
re-initiation

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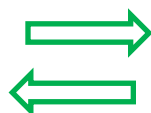
Actors involved in the ERN implementation



ERNs' Coordinators



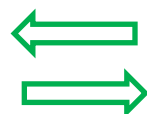
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ERNs
BoMS



National
Healthcare
System



Commission expert group on rare diseases



Patients
organisations



Professional /
scientific
organisations



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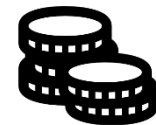
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ERN Board of MS: topics & agenda 2017

- Affiliated partners (1st September 2016) (2nd -March 2017)
- ERN & Industry
- ERN IT platform
- ERN monitoring and assessment system (June 2017)
- Link national networks/highly specialised centres to ERNs
- Support to Network coordinators and members of the ERN





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ERN's IT Platform and tools (under development)



IT tools

CLINICAL
Online patient
management

July
2017

Web/video conferencing , Virtual clinical meetings

**Exchange of Images (Radiology),
diagnostic tests & pictures (genetics,
pathology etc., (PACS)**

**Exchange of clinical information and
patient data**

**Communication
and
collaboration**

March
2017

Management /governance tools

Communication/conferencing tools



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Funding/support



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THE THIRD HEALTH PROGRAMME 2014-2020
FUNDING HEALTH INITIATIVES



EUROPEAN UNION
STRUCTURAL FUNDS



Erasmus+

Health and
Food Safety

Next steps



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ERN week: Vilnius 8-10 March

Board : 8 March

Conference: 9 March

Kick-off of the Networks: 10 March

Patient registries: grants deadline March

ERN Coordinators Group

launch 8 March

meetings & workshops (4-5 in 2017)

Call for new HCPs Nov 2017



new call for HCPs
to join existing
ERNs

3rd ERN Conference Vilnius, Lithuania 9 March

- Political support: Commissioner, EP, Council: Ministers LT & MT)
- Four roundtables
 - ✓ Operating ERN: organisation and management
 - ✓ EU Policies and Supporting Actions to the ERN
 - ✓ ERNs and national healthcare systems
 - ✓ ERN: The way Forward
- Award Ceremony



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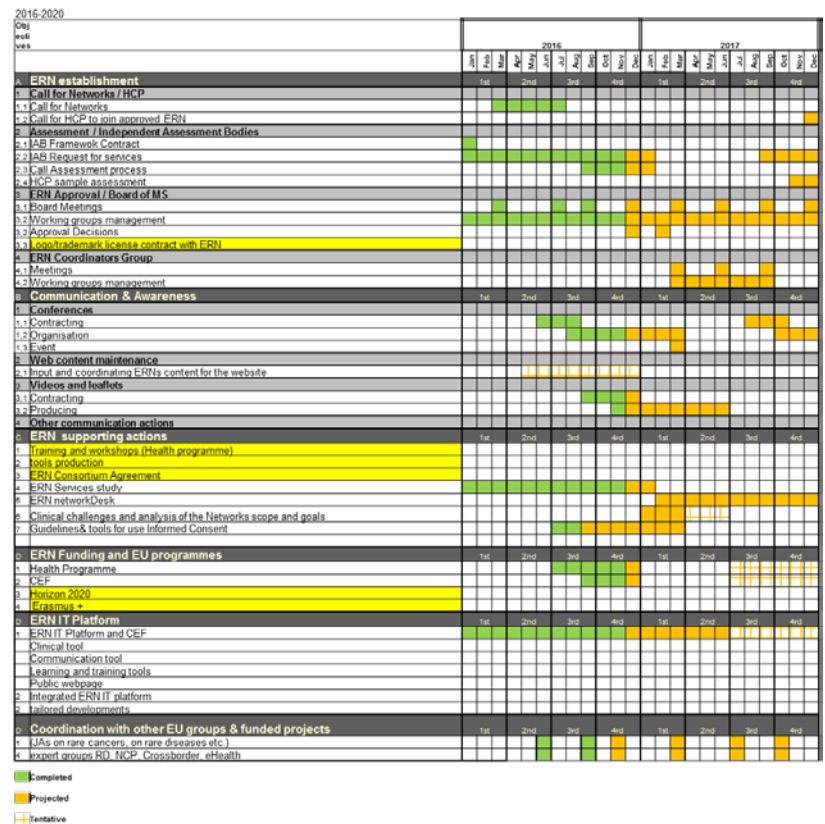


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5 year planning

European Reference Networks: Project implementation

- Integration of policies
- Funding
- Tools
- Member States role
- Network outcomes



Challenges



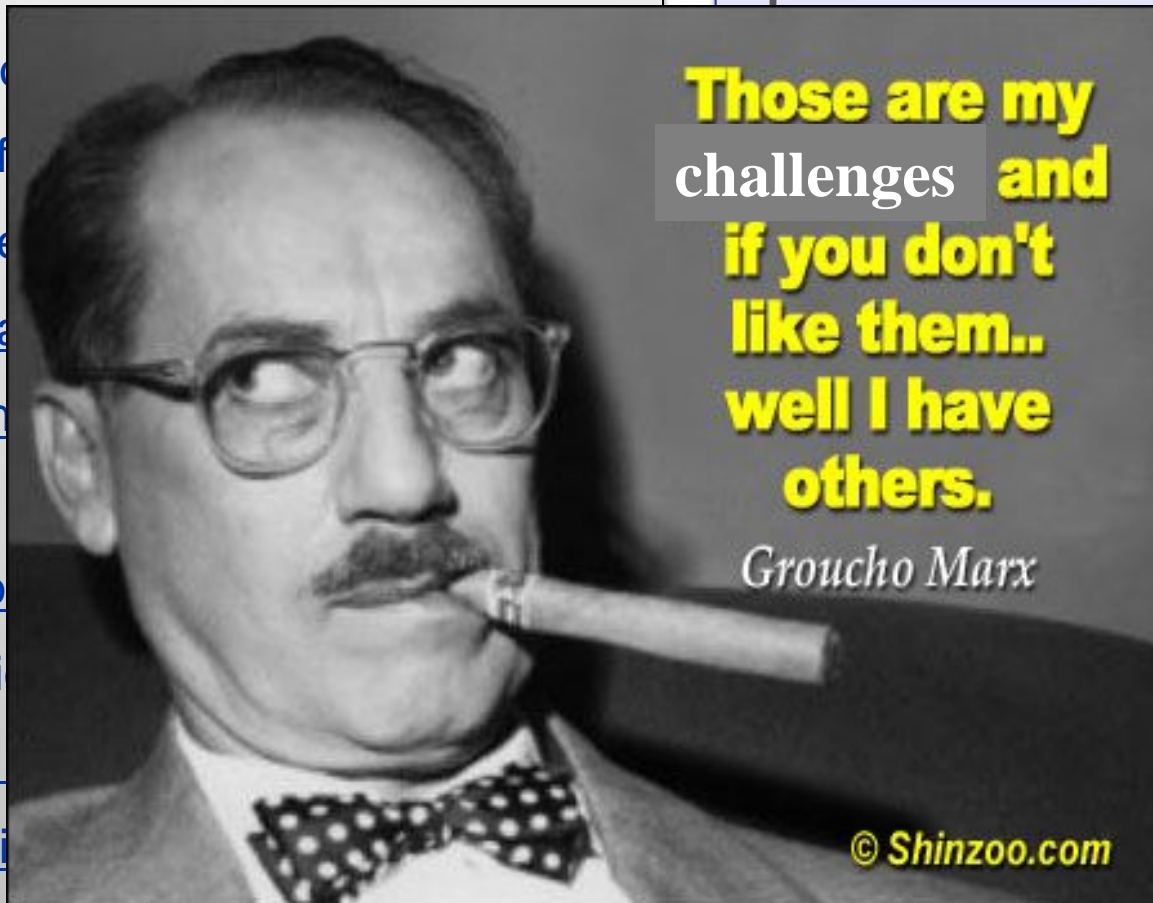
General Framework

- ✓ Definition of
- ✓ Referral of
- CBHC Dire
- ✓ ERNs & na
- Integration
- ✓ Liability &
- ✓ ERN IT so
- ✓ Coordination
- ✓ UK HCPs
- ✓ Sustainability

for continued funding post-2022

Specific tasks of ERNs

nt (coordinators)
e
in the Network
ation &
patient pathways
guidelines
ship





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**Thank you for
your attention**

Further information:



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



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