

THE ROAD TO ERNS



What is a European Reference Network?

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- “A network connecting providers of highly specialised healthcare (centres of expertise) in domains where patients and expertise are scarce”
- Concept grounded in ‘Cross-Border Healthcare Directive’ – ultimate form of planned CB care for complex conditions requiring a particular concentration of resources
- Many stakeholders stand to benefit:
 - ERNs should reduce inequalities for patients
 - For clinicians who network widely already, ERNs will formalise networking structures/practices
 - For those without specialist networking communities at present, ERNs will promote expertise and build collaborations
 - For industry and regulators, formal -and permanent- concentration of expertise

CURENet

eb Clinet
Linking clinical expertise in EB.

TREAT-NMD
Neuromuscular Network

EN-RBD

EuroCareCF
European Coordination Action
for Research in
Cystic Fibrosis



European Skeletal Dysplasia Network

CARE-NMD

ecorn-cf.eu
Expert Advice on Cystic Fibrosis

Epnet

EuroCYST
bringing knowledge -
improving outcome

A network of centres of expertise
dyscerne
for dysmorphology

EUHANET
Improving the care of European citizens
with inherited bleeding disorders.

EUROFEVER PROJECT
EUROFEVER
PEDIATRIC RHEUMATOLOGY
INTERNATIONAL COOPERATION
PERS
PEDIATRIC RHEUMATOLOGY
EUROPEAN SOCIETY
European Agency for
Health and Consumers



NEUROPED

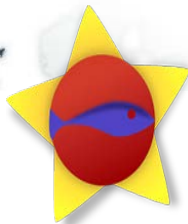
HD EUROPEAN
HUNTINGTON'S
DISEASE
NETWORK

EUNEFRON
European Network for the
Study of Orphan Nephropathies
www.eunefron.org

EHN Euro-Histio-Net
A reference network for Langerhans Cell
Histiocytosis and associated syndromes.

EIMD
European registry and network for
intoxication type Metabolic Diseases

PEDDCReN
Paediatric European Digestive Diseases Clinical Research Network



PRINTO

nerca
European Network for Rare
and Congenital Anomalies

EuroWilson

EURen Omics

www.rd-action.eu

Information Network on Rare Cancers
RARECARENet

SWEET PEDIATRIC DIABETES
ACTION
DATA AND POLICIES
FOR RARE DISEASES

Road to ERNs

- CBHC Directive – 2011
- 2014 – Implementing & Delegated decisions outline the process of how to become a member of an ERN
- 2015 – Joint Action & CEGRD Addendum ‘model’ to group diseases published:

Rare immunological and auto-inflammatory diseases
Rare bone diseases
Rare cancers* and tumours
Rare cardiac diseases
Rare connective tissue and musculoskeletal diseases
Rare malformations and developmental anomalies and rare intellectual disabilities
Rare endocrine diseases
Rare eye diseases
Rare gastrointestinal diseases
Rare gynaecological and obstetric diseases
Rare haematological diseases

Rare craniofacial anomalies and ENT disorders

Rare hepatic diseases

Rare hereditary metabolic disorders

Rare multi-systemic vascular diseases

Rare neurological diseases

Rare neuromuscular diseases

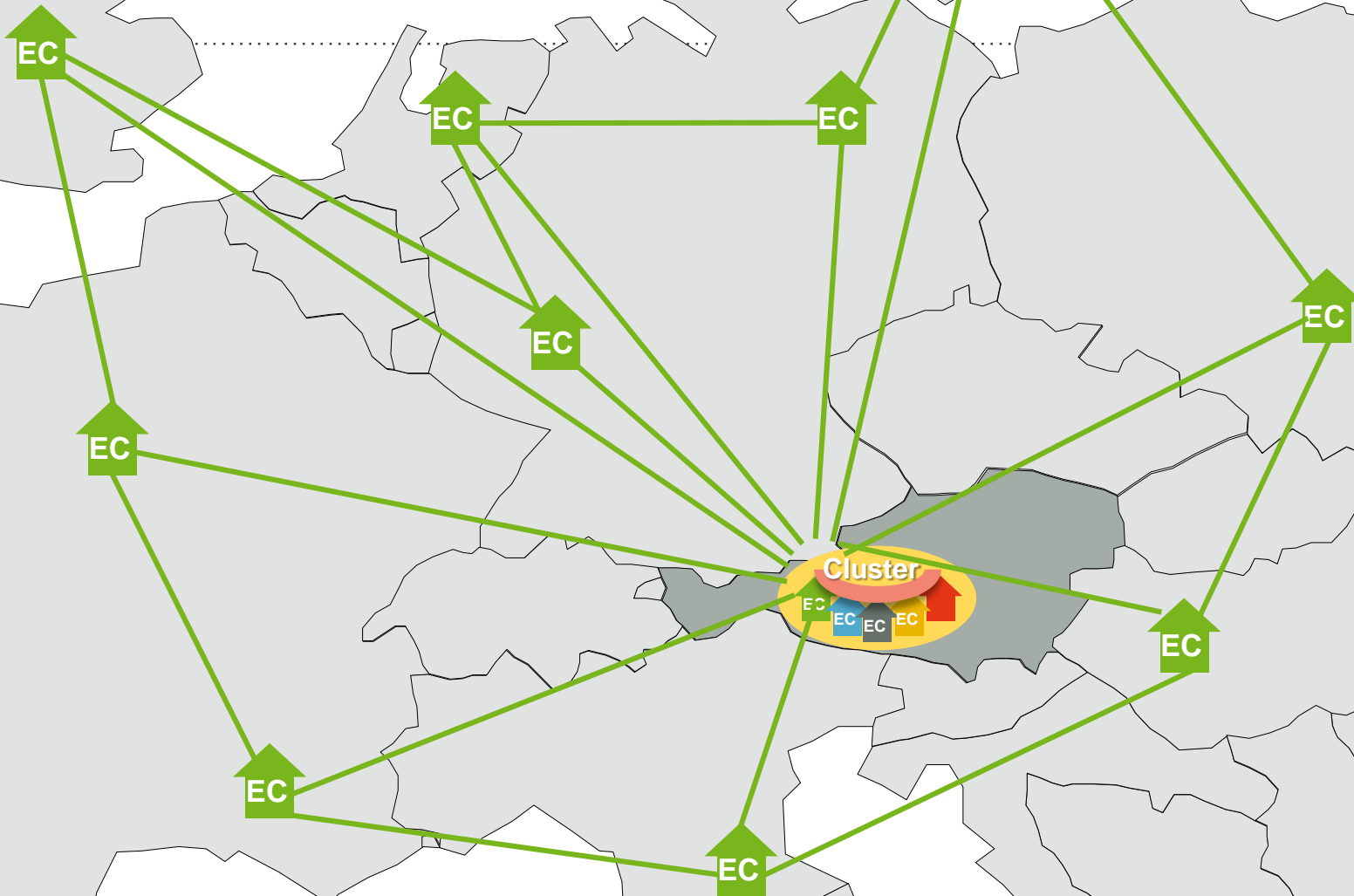
Rare pulmonary diseases

Rare renal diseases

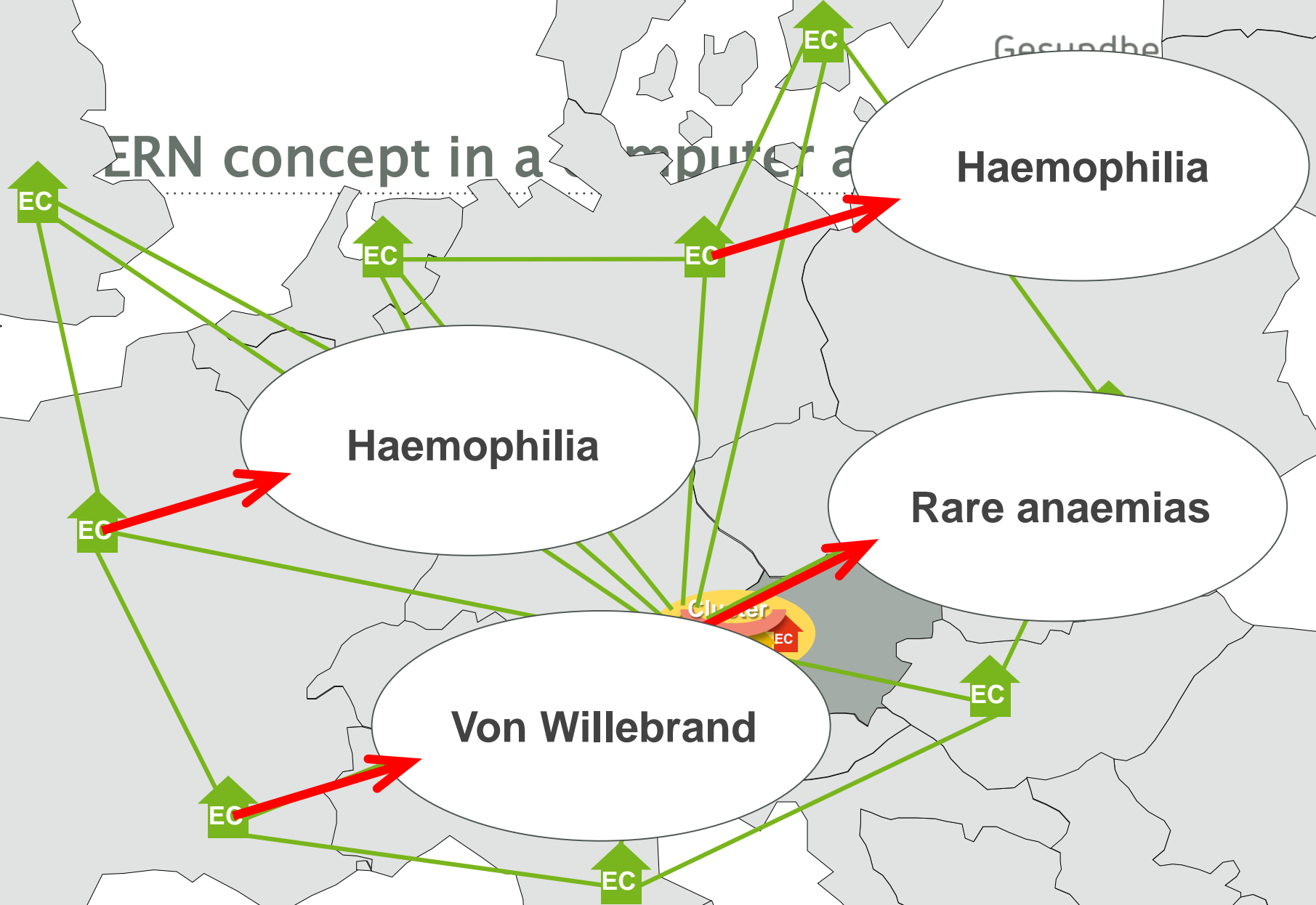
Rare skin disorders

Rare urogenital diseases

Voigtlaender slide to demonstrate ERNs



ERN concept in a computer a



Gesundhe

Haemophilia

Haemophilia

Rare anaemias

Von Willebrand

Cluster

EC

EC

EC

EC

EC

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EC

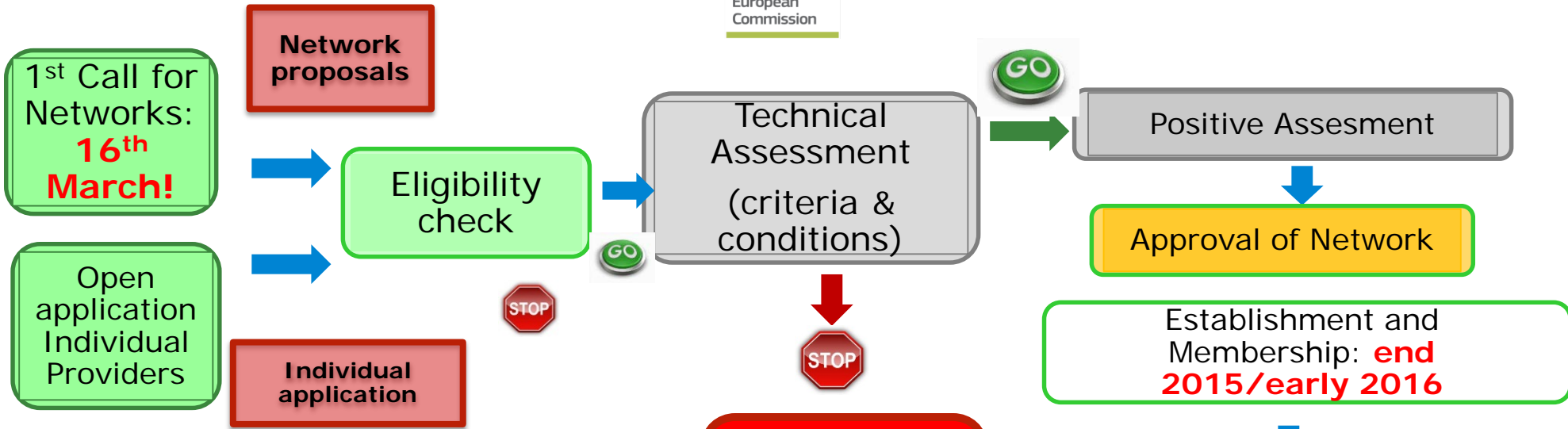
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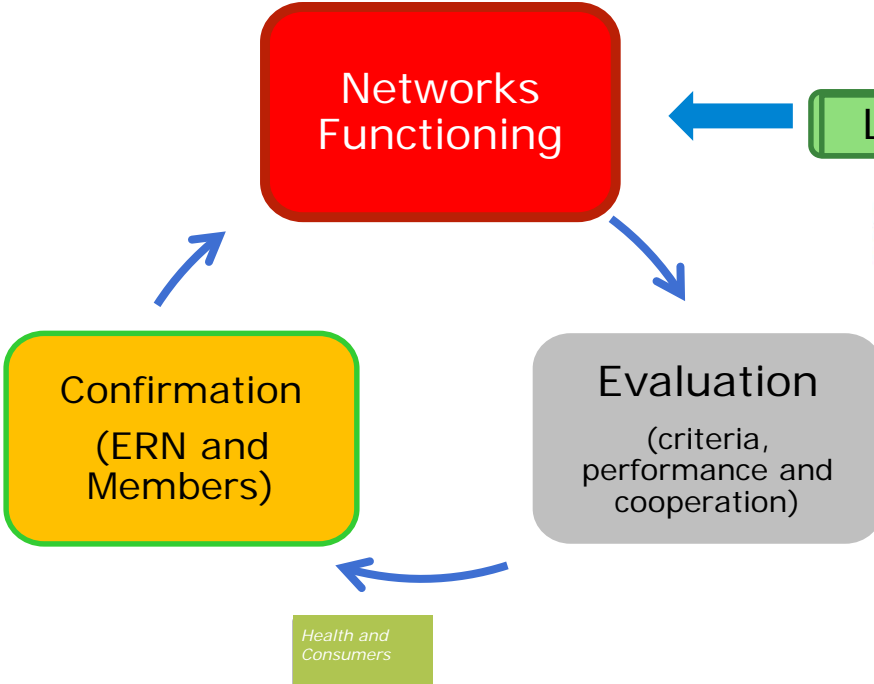
Road to ERNs

- End of 2015 – RD-ACTION Matchmaker
- March 2016
 - Assessment Manual and ToolKit published:
 - PH Programme Funding
 - Call on 16th March

ERN Scenario



- Players**
- 1 **HCP & Network projects**
 - 2 **SANTE**
 - 3 **Member States**
 - 4 **Technical Independent Body**





Network criteria and capacities

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- ✓ knowledge and **expertise to diagnose, follow up and manage patients**
- ✓ Evidence of **good outcomes**
- ✓ **multi-disciplinary** approach
- ✓ capacity to **produce good practice guidelines and to implement outcome measures and quality control**
- ✓ collaborate with **other centers of expertise and networks**
- ✓ **Research, teaching and training**



ERNs & Research



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- ERNs hold huge potential to redefine healthcare and research environment
- ERNs will formally unite field leaders & **provide unparalleled opportunity to collect and share anonymised, high-quality data for research.**
- ERNs should contribute to research infrastructures like RD-Connect & become key users
- RD-ACTION Policy WP exploring how to support ERNs in world-leading research: several good practices one could recommend:
 - contribute omics and clinical data to the RD-Connect platform to support research and in turn utilise this platform to confirm diagnoses for their patients.
 - Consent patients to annotate, store and catalogue biosamples with appropriate **biobanks.**
 - Use 'IRDiRC recommended' assets
 - Promote use of RD-appropriate ontologies
 - Collect data to ensure compatibility with GUID