



# SETTING THE SCENE – EASTERN EU DIMENSION OF ERNS

**Matt Bolz-Johnson,  
EURORDIS**

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# Cross-border Healthcare – Setting the Scene



**Common challenges** facing NHS systems are a **growing aging population & budgetary constraints**



**Cross-border regions** represent 40% of the territory of the EU; with 1 in 3 Europeans live in a border region.



**EU-level cooperation:** Council of the European Union in 2011 emphasised “the need to join forces and enter into **more coordinated EU-level cooperation** in order to support Member States”



**EU Member States** need to **deepen cross-border healthcare cooperation**, stimulate **exchange of best practices** and **enhance the cohesion** between border regions through the creation of an **EU cross-border mechanism**

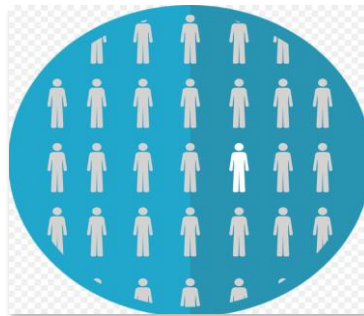
# Cross-border Cooperation under the CBHCD

## ERNs



- 24 European Reference Networks
- EU flagship initiative
- Pooling of knowledge
- Launch of ERNs marked a major change in the delivery of healthcare cross-border to EU citizens

## Rare Diseases



- Increase public awareness of rare disease
- Increase funding for R&D
- European Joint Programme on Rare Diseases

## HTA



- Health Technology Assessments
- EUnetHTA network for HTA across EU
- Legislative proposal on Health Technology Assessments by the EC

## eHealth

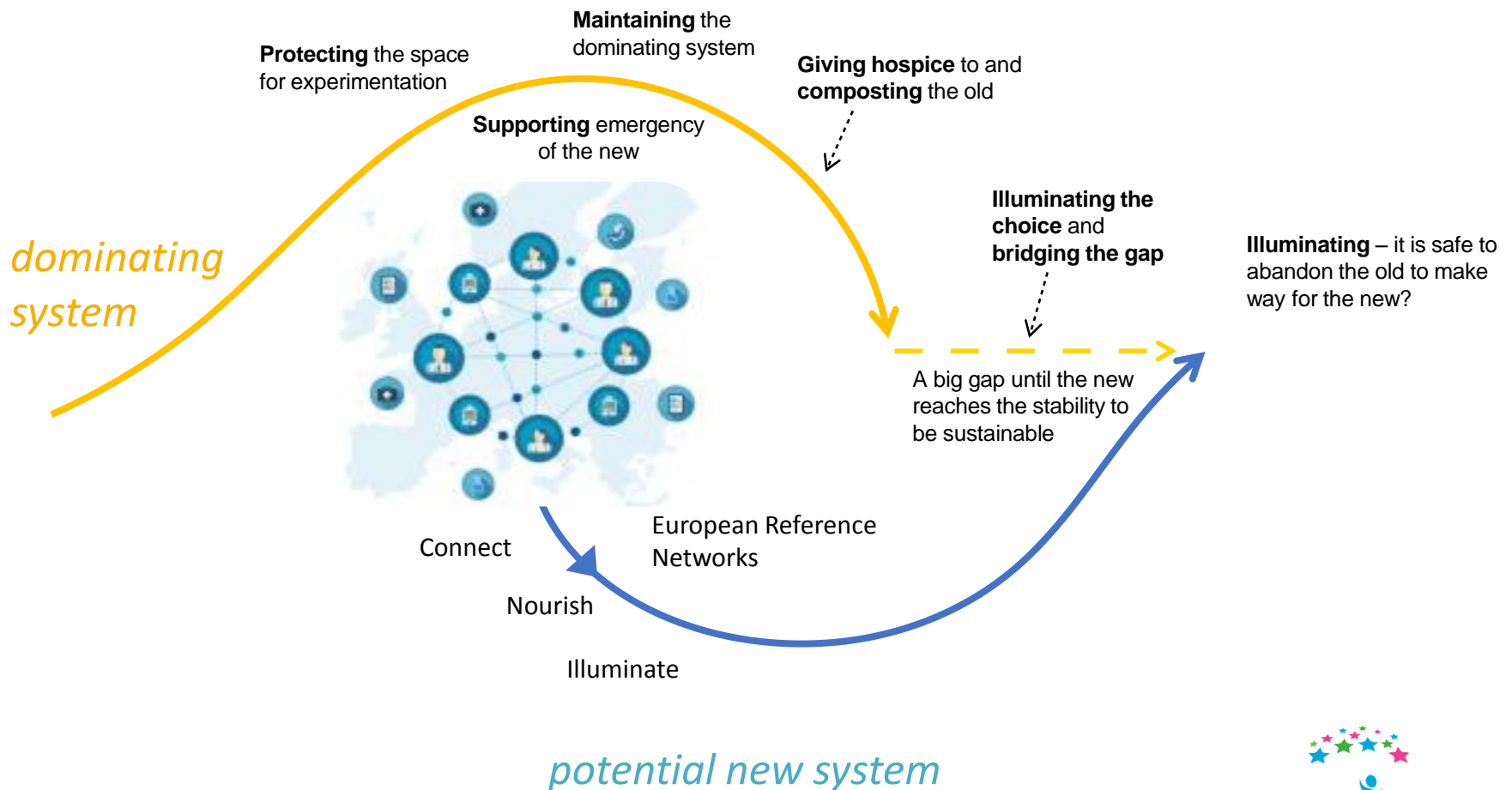


- eHEALTH
- ePrescription and Discharge Summary
- Challenges ICT adoption & specific to complexity, governance, local conditions and stakeholder engagement

# ERN: A Paradigm Shift in Healthcare Delivery

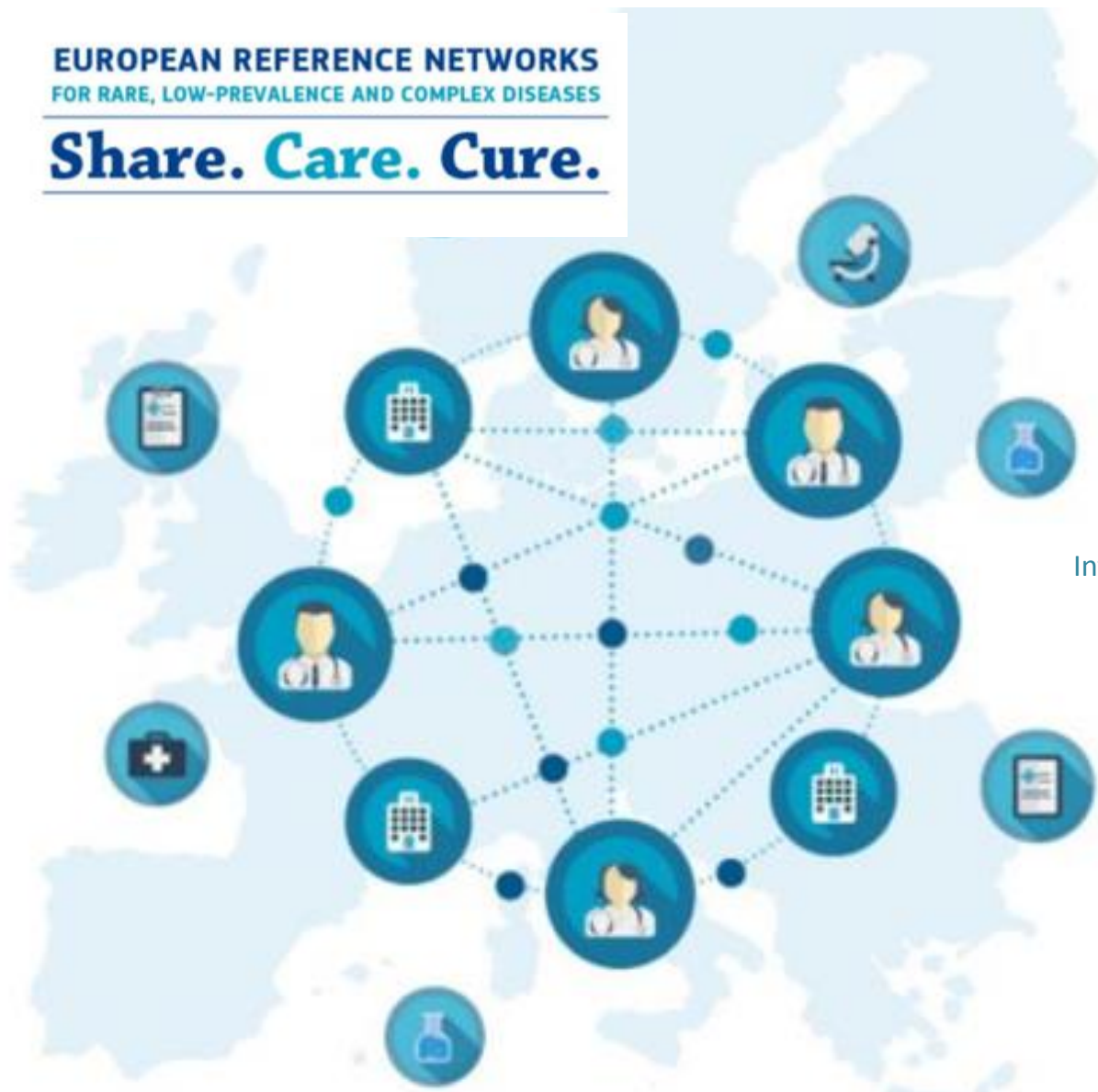
Berkana Institute  
Two-Loop model

*A system is inclined to self preservation.*



**EUROPEAN REFERENCE NETWORKS**  
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES

**Share. Care. Cure.**



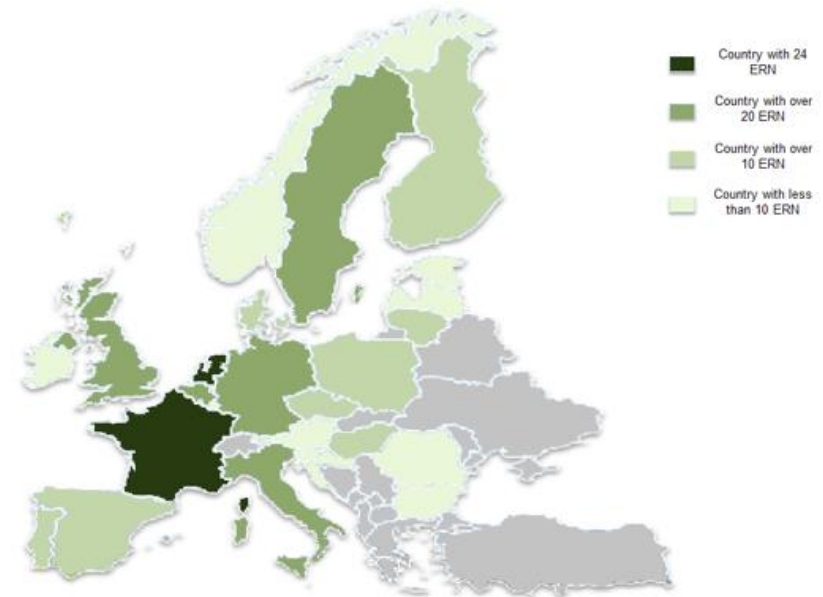
- Rare Bone 1.
- Rare Cancer 2.
- Pediatric Cancer 3.
- Rare Cardiac 4.
- Rare Connective Tissue 5.
- Rare Craniofacial & ENT 6.
- Rare Endocrinology 7.
- Rare & Complex Epilepsy 8.
- Rare Eye 9.
- Rare Gastrointestinal Diseases 10.
- Rare Hematology 11.
- Rare Hepatic Diseases 12.
- Rare Immunodeficiency, Auto Inflammatory & Autoimmune Disease 13.
- Genetic Tumours 14.
- Rare Malformations & Development Anomalies 15.
- Rare Hereditary Metabolic Diseases 16.
- Rare Neurology 17.
- Rare Neuromuscular 18.
- Rare Pulmonary Diseases 19.
- Rare & Undiagnosed Skin Disorders 20.
- Rare Renal 21.
- Transplantation in children 22.
- Rare Urogenital Diseases 23.
- Rare Multi-systemic Vascular Diseases 24.

- 24 European Reference Networks
- 900 HCP Member in 26 Member States

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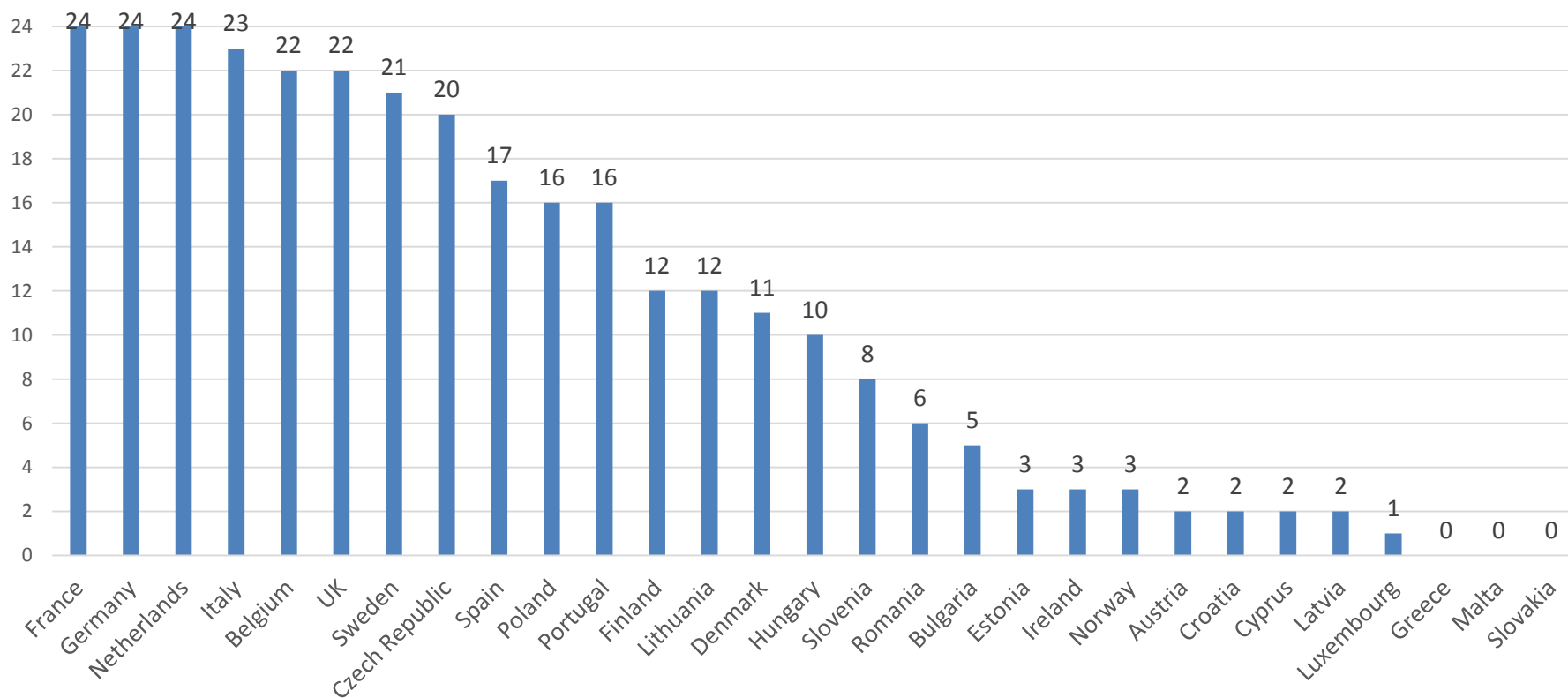


# HCP Members in ERNs



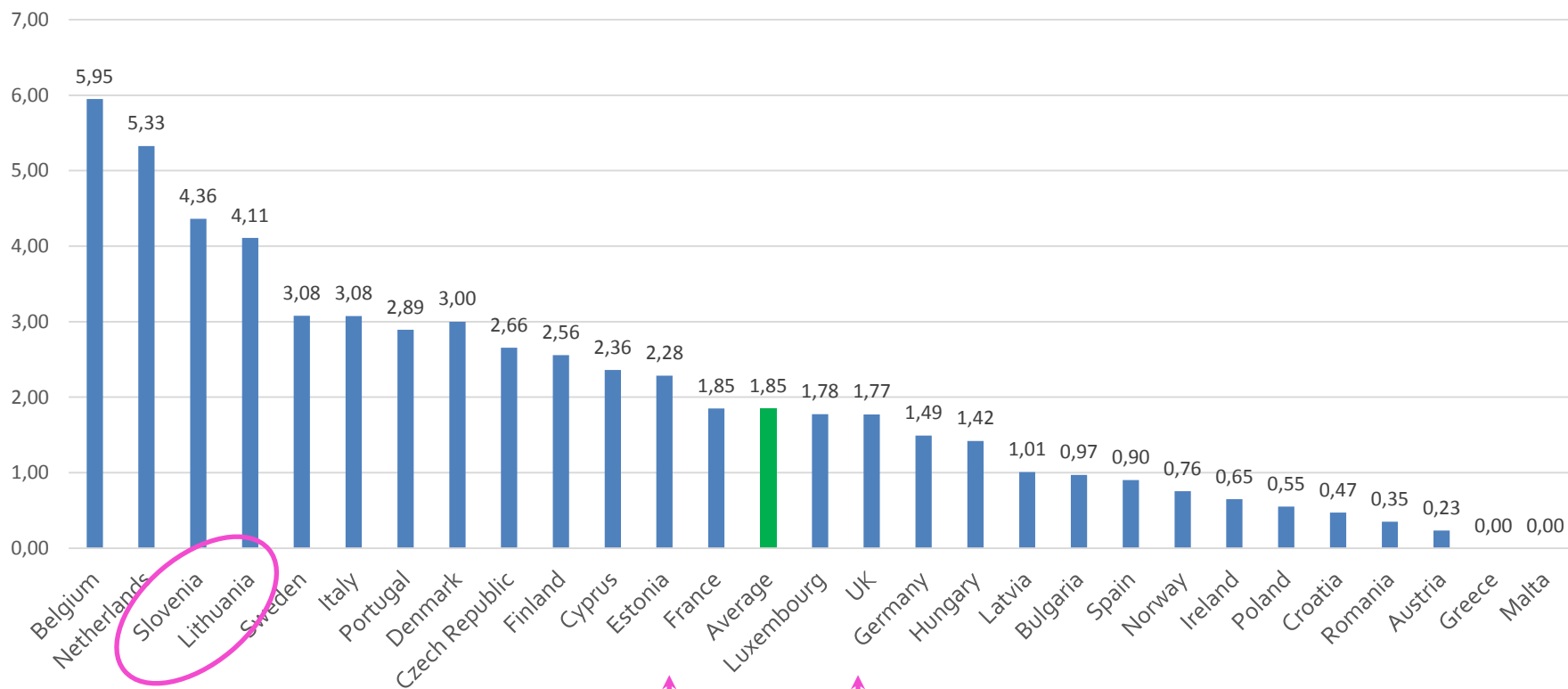
- Total EU Population 743,040,568 (2019) – Higher population in Western EU MS
- 24 ERNs connecting 900 HCP Members in 300 Hospitals, across 26 Member States
- 24/24% ERN are coordinated by a western EU MS HCP Members
- 70% ERN HCP Members from 5 MS: France, Italy, Germany, The Netherlands and U.K.

# Coverage per MS - Number of ERNs where the MS has at least 1 expert centre (unit)



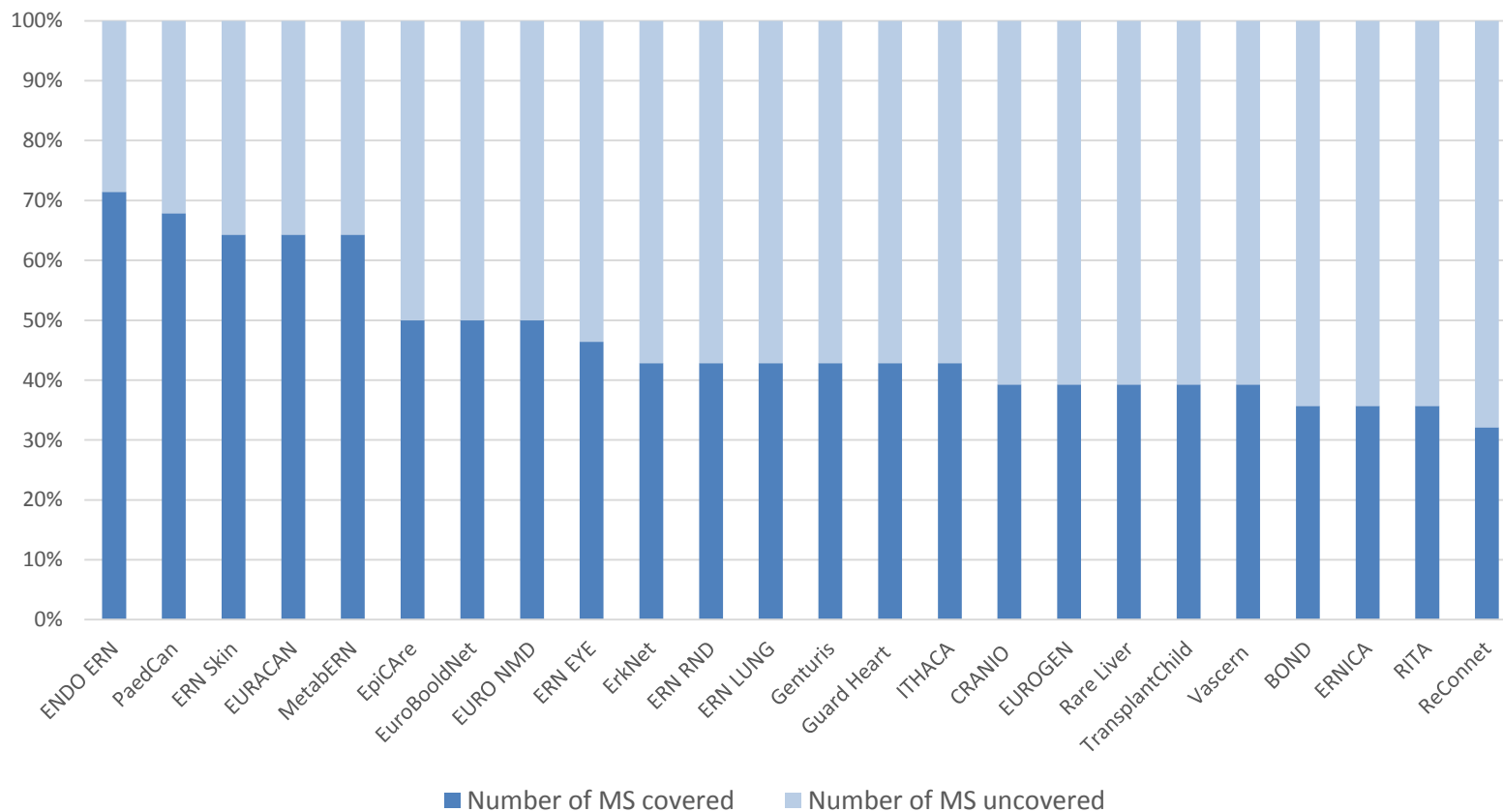
# Coverage per MS – ERNs per 1 million inhabitants

Number of Expert Centres in ERNs (Units) per 1 million inhabitants



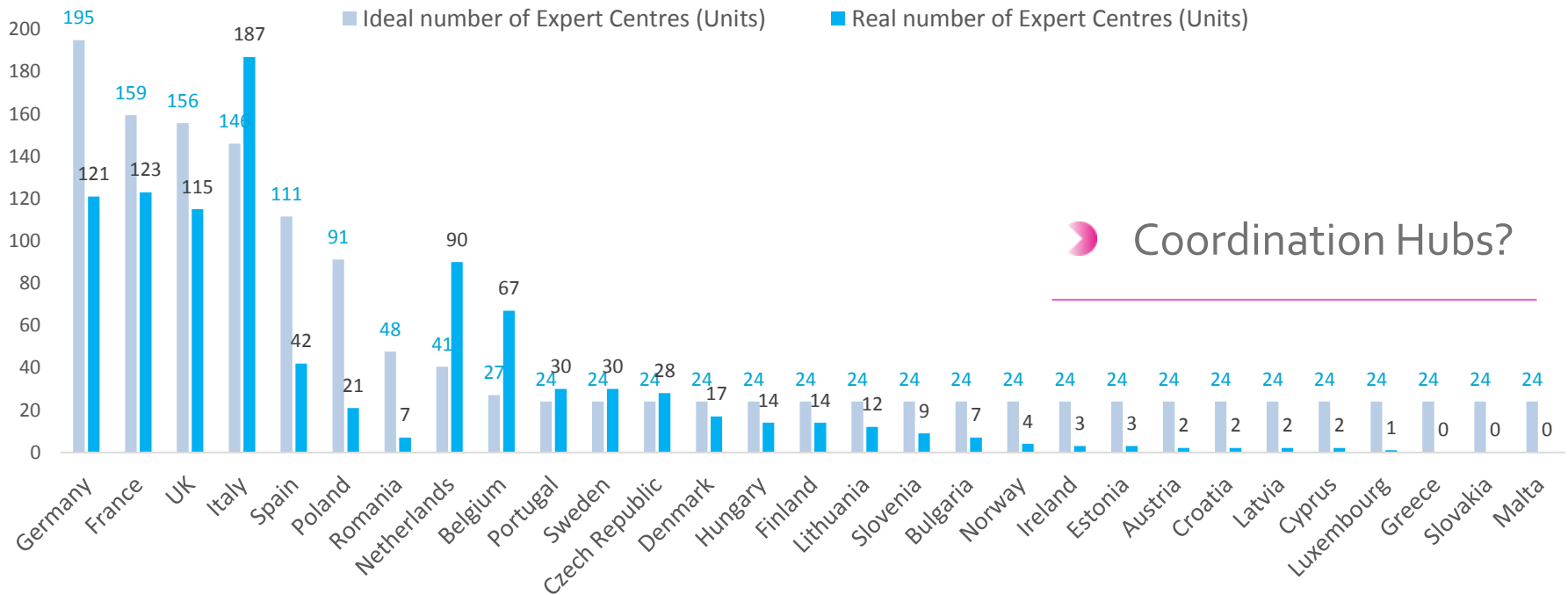


# Number of countries represented in each ERN



- Best one, has at least one HCP in 20 MS - plenty of room for improvement
- Inequities in geographical distribution within some ERNs, for example EuroBloodnet has 21 Italian HCPs out of 65

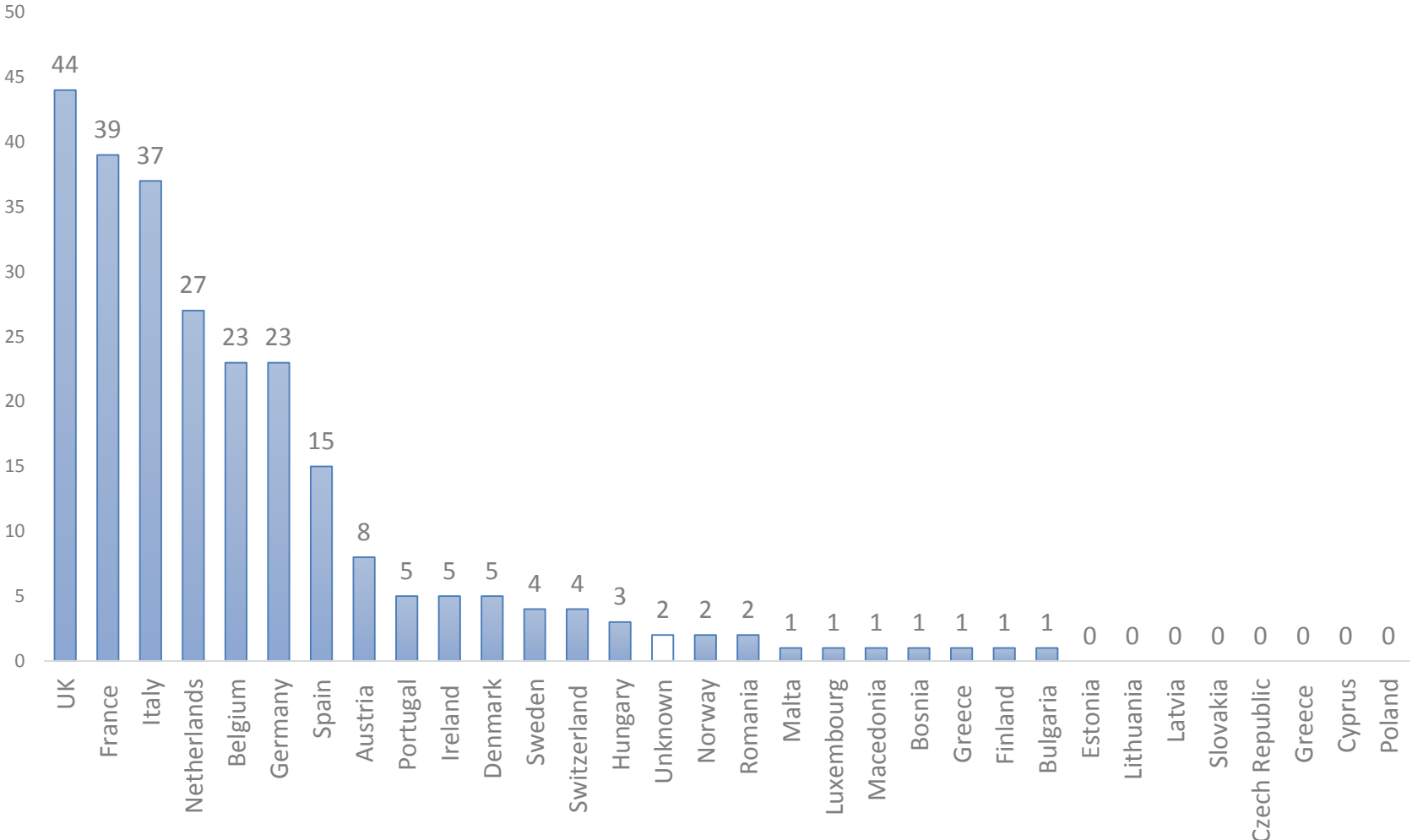
# Real versus Ideal number of Expert Centres per country



Coordination Hubs?

Coordinators hypothesis: 1 Expert Centre per ERN per 10 million inhabitants or 1 centre per ERN in the smaller MS

# Number of ePAG Patient Advocates per Country



## In Summary:



- ▶ **European Reference Networks** are seen as the EU flag-ship initiative - *European Parliament CBHCD Resolution, 2019*:
  - Further development and financing of the ERNs
  - Scaling up the ERN model up - universal coverage of EU MS and all Rare Diseases
  - Expansion of the ERN model New Call for new ERNs
  - Need to establishing clear, transparent rules for patient referral between NHS & ERNs.
- ▶ **Timeline for Expanding ERN Members (2019)**:
  - Affiliated partners – MS to designate affiliated expert centres between Autumn 2018 - Spring 2019
  - EC Call for New HCP Members – estimated in May/June 2019

# ERN Board of Member States Perspective

Dr. Pfliegler, ERN Board of Member States  
Representatives, Hungary

# Clinical Lead (ERN) Perspective

**Dr Birute Tumiene, Clinical Geneticist, Vilnius  
University Hospital & ERN Board of Member States  
Representatives, Lithuania**

# Patient Representative Perspective

Ms Petia Stratieva, Retina International & Bulgarian  
National Alliance, Bulgaria

# Session 1 – State of the Art: Eastern Countries involved in ERNs

09:30 – 10:30

## Roundtable discussion:

- *Why do you believe we need ERNs and what can we hope for from them?*
- *How will people living with a rare disease and hospitals in Eastern and Central EU MS benefit from the ERNs?*
- *What is the vision of success you see for ERNs with particular focus on non-western EU MS?*

## Closing Remarks from each panellist



# Thank You



# Session 2 – Ask the expert: Opportunities & Barriers Roundtable

11:00 – 12:30



# Session 2 – Ask the expert: Opportunities & Barriers Roundtable

11:00 – 12:30

- Opening Remarks – Dr Birute Tumiene, ERN BoMS Representatives, Lithuania, Session Chair
- ERN BoMS Representative - Dr. Pfliegler, ERN BoMS Representatives, Hungary
- ERN ReCONNECT HCP Member - Dr Laura Damian, MD, PhD, Rheumatology Consultant in the Emergency Clinical County Hospital Cluj, Romania
- ePAG Patient Representative(s) - Dorica Dan, Romanian National Alliance & Gábor Pogány, Hungarian National Alliance
- Followed by a roundtable discussion and Q&A.

# Opening Remarks - Session Chair

**Dr Birute Tumiene, Clinical Geneticist, Vilnius  
University Hospital & ERN Board of Member States  
Representatives, Lithuania**

# ERN Board of Member States Perspective

Dr. Pfliegler, ERN Board of Member States  
Representatives, Hungary

# ERN HCP Member Perspective

**Dr Laura Damian, MD, PhD, Rheumatology  
Consultant in the Emergency Clinical County  
Hospital Cluj, Romania & ERN ReCONNECT HCP  
Member**

# ePAG Patient Representative's Perspective

**Ms. Dorica Dan, Romanian National Alliance &  
Mr. Gábor Pogány, Hungarian National Alliance**

# Session 3 – Working Groups – Country Level Needs for Eastern Countries to participate in ERNs?

13:30 – 15:30





# Session 3 – Working Groups – Country Level Needs for Eastern Countries to participate in ERNs?

13:30 – 15:30

## Eastern European Countries Working Group (1) – XXX Room:

- led by Dorica Dan, Dr Birute Tumiene & Matt Bolz-Johnson (rapporteur)

## Central European Countries Working Group (2) – XXX Room:

- led by Gábor Pogány, Dr. Pfliegler & Inés Hernando (rapporteur)

## Working Group Key Aims:

- *How to increase involvement of patients and clinicians in ERNs from Eastern & Central European Countries?*
- *How to integrate ERN into National Systems?*
- *To identify key barriers & opportunities.*
- *To identify key immediate actions to be taken*

# Session 4 – Summary & Key Messages Session

15:30 – 16:30

Two Groups Reporting back – drawing out key issues and opportunities for the panel discussion:

- **Eastern European Countries Working Group (1)** – Matt Bolz-Johnson (reporting back)
- **Central European Countries Working Group (2)** – Inés Hernando (reporting back)
- Questions & Answers
- Closing Remarks
- Finish @ 16:30

# Muțumesc 😊

