

# European Reference Networks Presence and Future

## A Board of MS / MS perspective

ProMIS Summer School Strategy/Policy workshop 24.06 2022

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ProMIS Summer School 2022 „The internationalisation of health systems: which evolution for the country system?“

Hotel Marechiaro, Lamezia Terme, Italy, 23.–24. June 2022

## A kind of disclaimer (1)

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- » There is no „View of the Board of Member States“
- » There are 27 MS views + 1 EEA State view (Norway)
- » There are 28 different healthcare systems
  - » Some centralized
  - » Some federal on a county level
  - » Some highly regional
- » Some views are common between most/all MS
- » Some MS expectations are highly diverse
- » ... at the end, **this reflects Europe**

## A kind of disclaimer (2)

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- » My attendance in the ProMIS summer school has **two main functions**:
  - » Invitation as speaker
  - » Participation to listen to **your thoughts regarding a new layer** in the care for people living with rare diseases: The creation of “**National Reference Networks**”

# Contents

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- » Definition of and challenges with rare diseases
- » European Reference Networks
  - » Characteristics
  - » Model (animated graphics)
  - » Activities – MS expectations
  - » Activities beyond MS expectations
- » Future challenges and perspectives
  - » Size and sustainability
  - » Integration into national healthcare systems

# Definition and challenges of RD

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## » Definition criteria:

### » Prevalence:

» Not more than **5 individuals per 10.000** inhabitants **in Europe** affected

### » Severity:

» A **life-threatening** or **chronically debilitating** condition

# Definition and challenges of RD

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## » Challenges:

### » Rare diseases are “Orphans”

- » Limited public and scientific awareness and knowledge
- » Delayed or lacking or wrong diagnosis
- » Delayed or insufficient or lacking or wrong care and therapy
- » Delayed or lacking prevention
- » **Scarcity, fragmentation and isolation of resources**
- » **Lack of evidence-based quality guidelines**  
(diagnostics, clinical care)

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## ERNs – main characteristics

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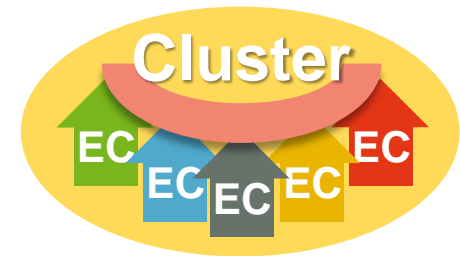
- » European-wide network consortia of highly specialized medical centres and units collaborating within 24 overarching thematic domains (e.g. “Rare skin diseases”)
- » Inclusion of centres specialized in paediatric and adult care
- » Each participating centre is required to provide a multidisciplinary and multiprofessional care approach
- » First example of a structured, legally based collaboration between European Member States in the healthcare sector
- » First and **main focus** is **provision of care** to patients



# The ERN model

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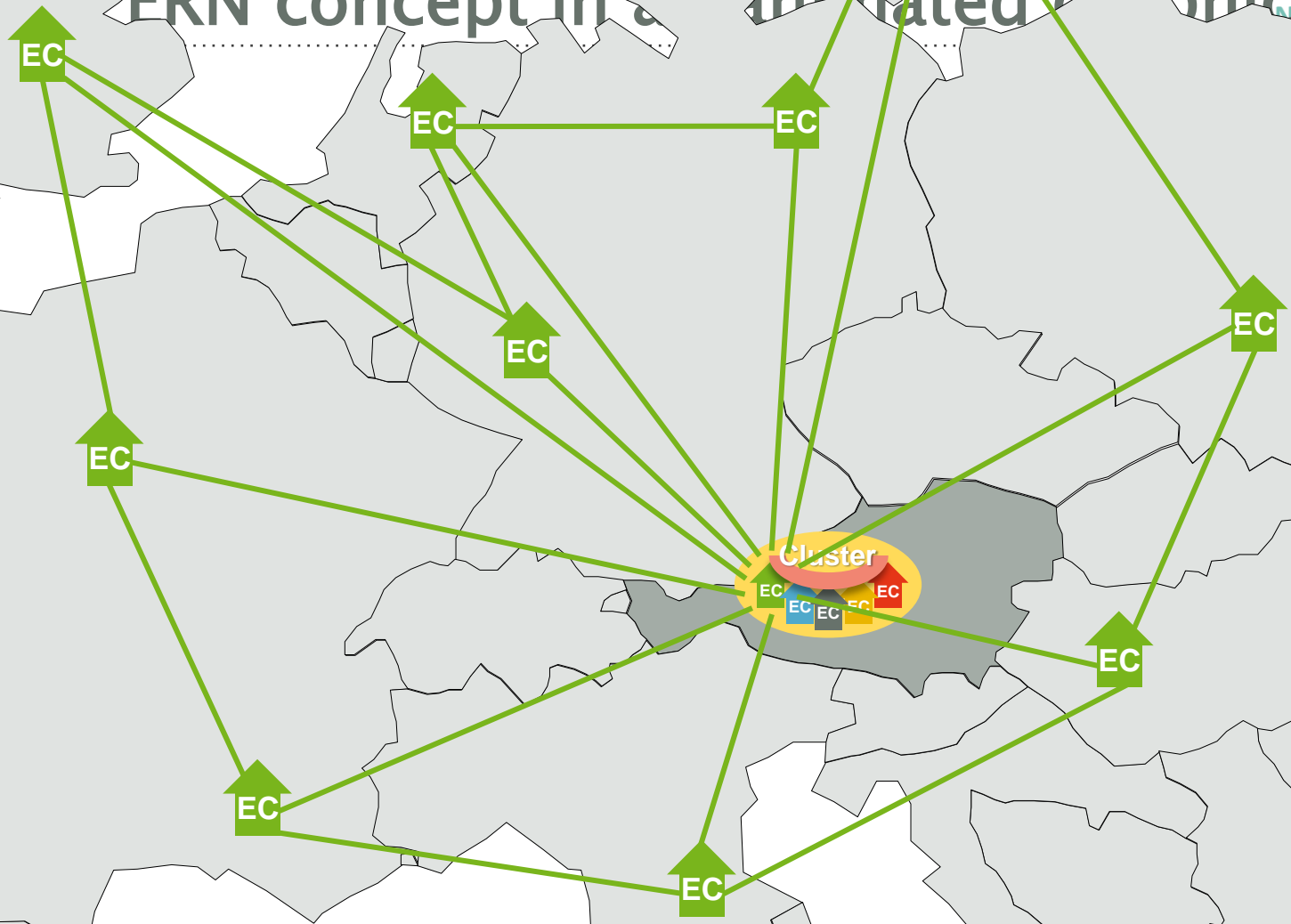
» Centres of Expertise



» European Reference Networks



# ERN concept in animated graphics



# ERN concept in dermatology

EC

EC

EC

EC

**Ichthyosis**

**Hair and nail anomalies**

**Inherited epidermolysis bullosa**

EC

Cluster

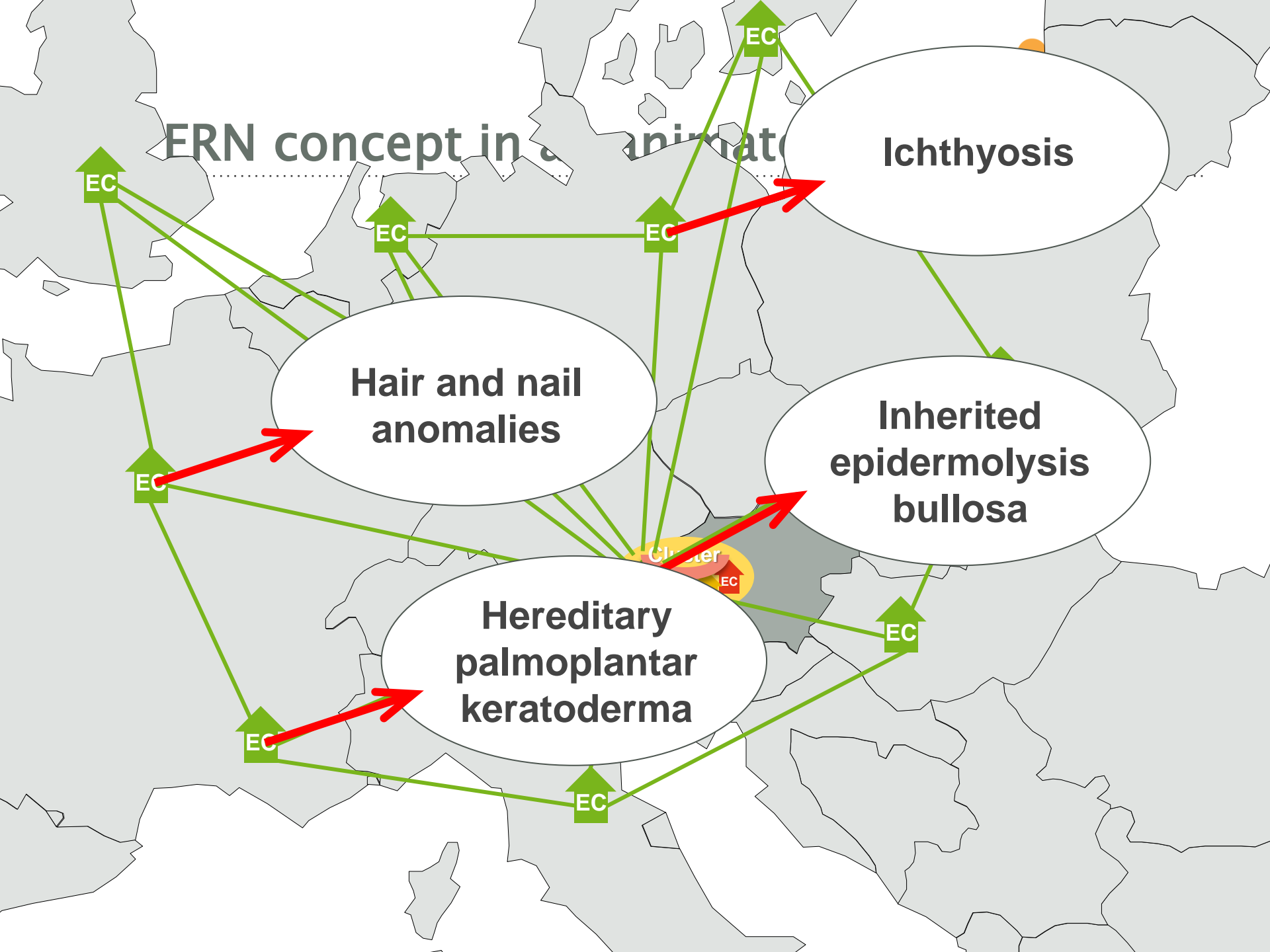
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**Hereditary palmoplantar keratoderma**

EC

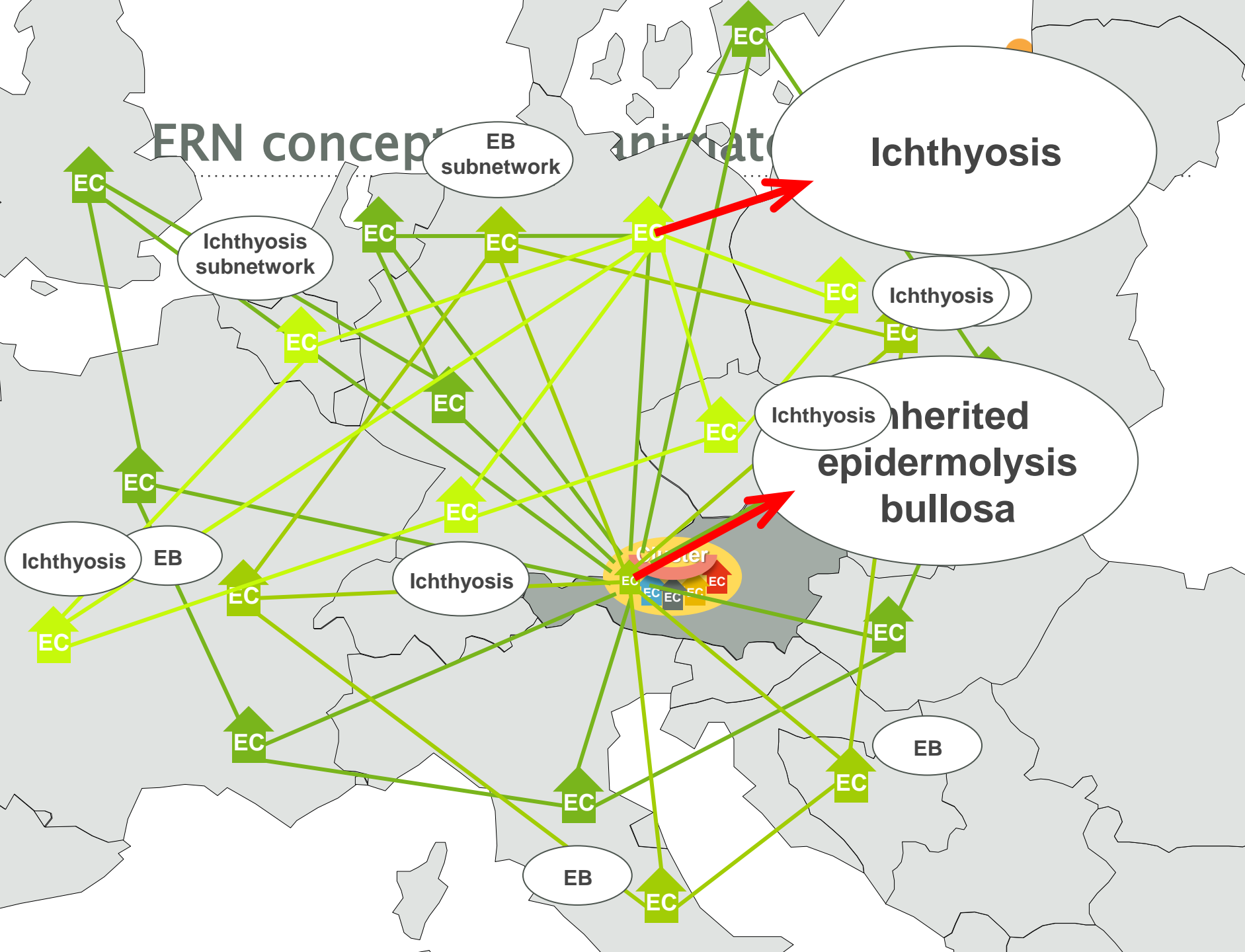
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ERN concept

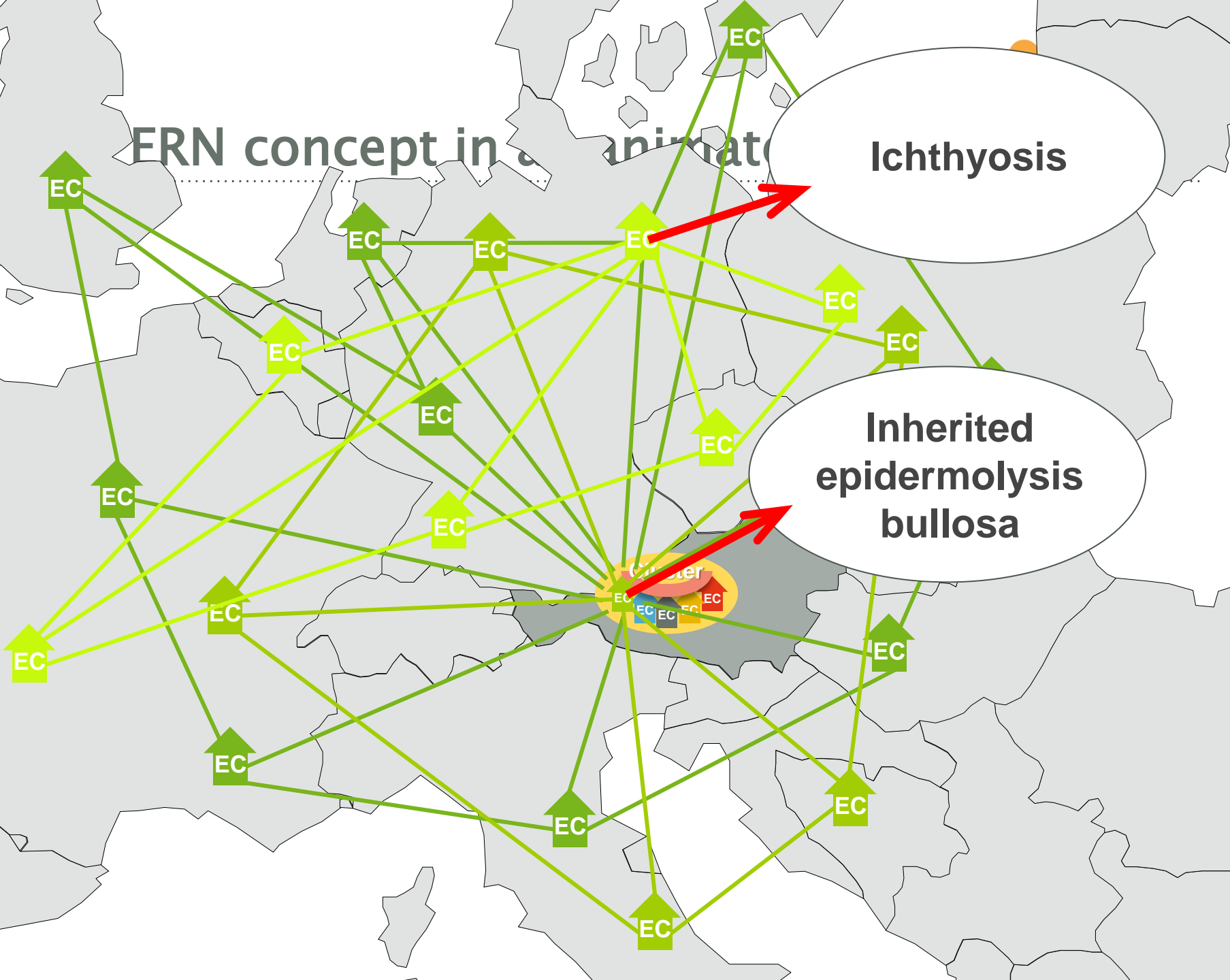
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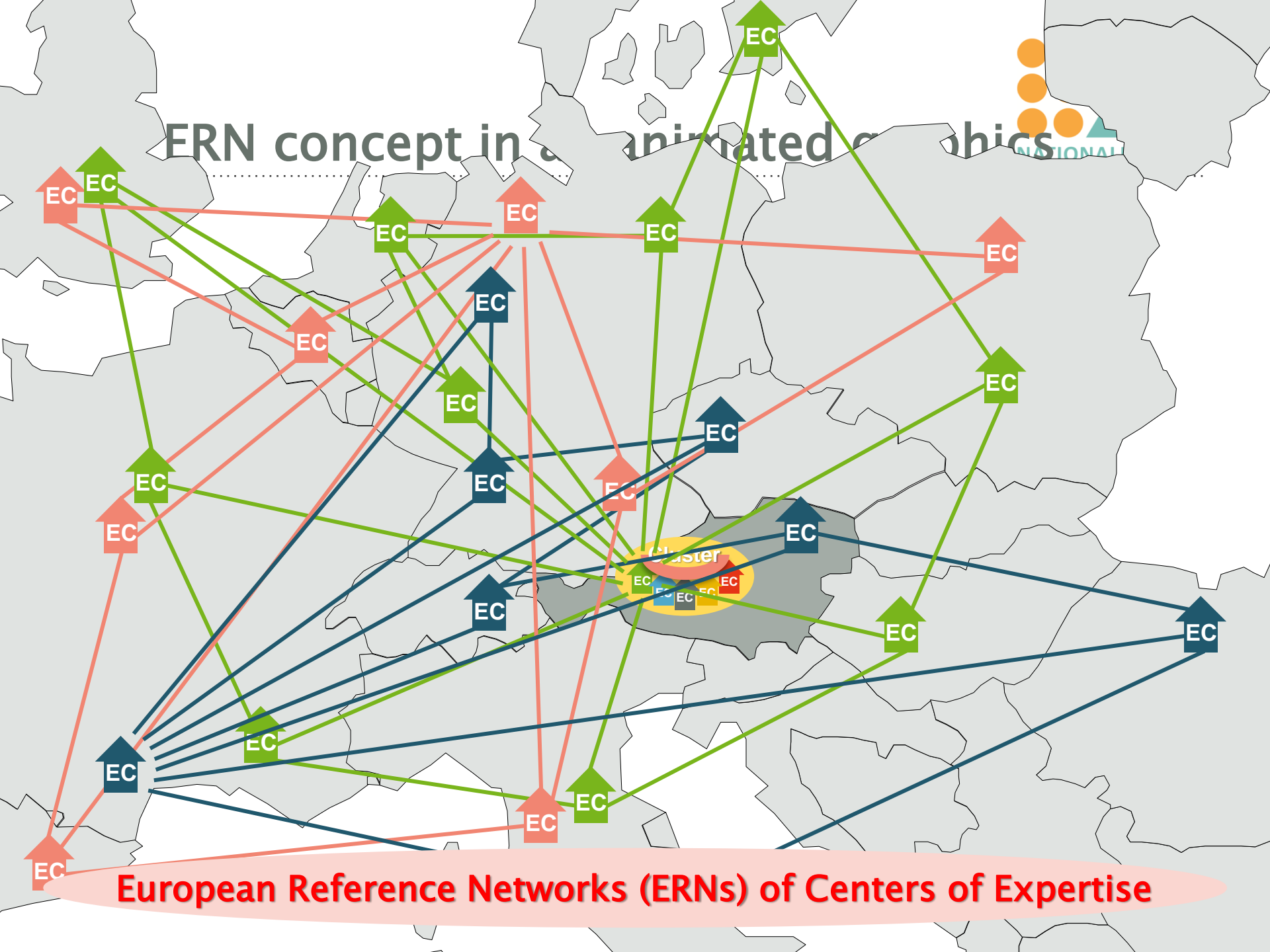
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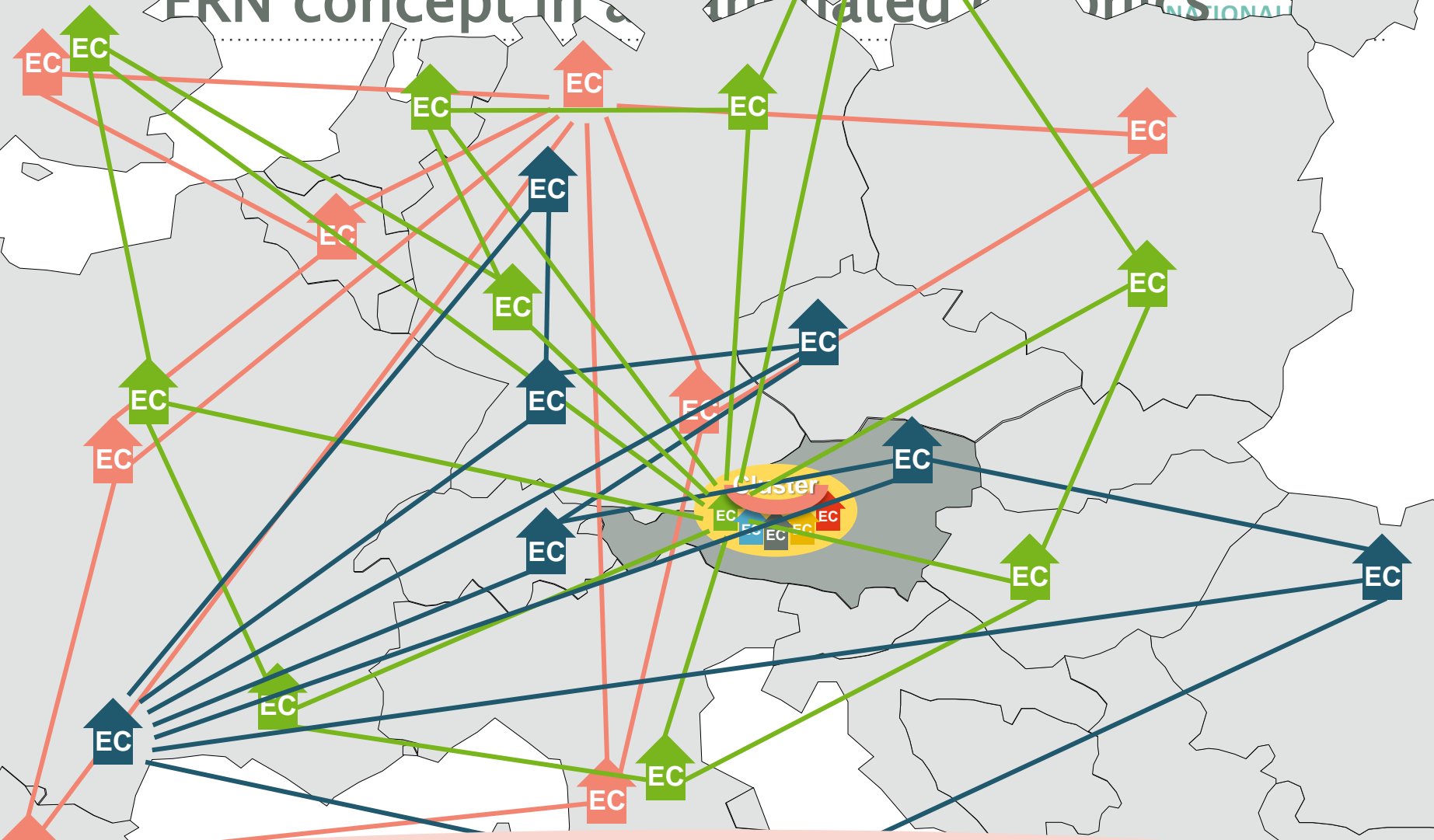


# ERN concept in animated graphics



**European Reference Networks (ERNs) of Centers of Expertise**

# ERN concept in animated graphics

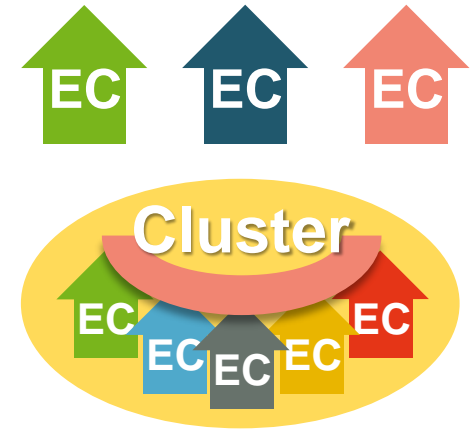


**European Reference Networks (ERNs) of Centers of Expertise**

# The ERN model

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» Centres of Expertise



» Associated National Centres



» European Reference Networks





# Activities of ERNs – MS expectations

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- » Support or direct provision of care for patients
  - » Virtual consultations (CPMS<sup>1</sup>)
  - » Cross-boarder physical care and therapies
- » Generation and expansion of knowledge
  - » ERN registries
  - » Generation and Dissemination of medical evidence
  - » Development of Clinical Practice Guidelines
- » Research
  - » Basic
  - » Preclinical
  - » Clinical
- » ERN-specific **education** and **professional training**

<sup>1</sup> Clinical Patient Management System

# Activities beyond MS expectations

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- » Acute and self-initiated responses to different health crises (supported by the European Commission)
- » **Covid-19** pandemic
  - » Launch of a “COVID-19 Clinical Management Support System” by the EC
  - » Production and recording of a live webinar series (“COVID-19 and ERNs”)
  - » Support for clinicians and other healthcare professionals at the frontline treating patients with Covid-19
  - » **Videos** available on the **EC website**:  
[https://ec.europa.eu/health/european-reference-networks/events\\_en?f%5B0%5D=topic\\_topic%3A140](https://ec.europa.eu/health/european-reference-networks/events_en?f%5B0%5D=topic_topic%3A140)



## Public Health

[European Commission](#) > [Public Health](#) > [European Reference Networks](#) > [Events](#)

### European Reference Networks - Events

#### Filter by

##### Keywords

##### Status


##### Event date

##### Subject

##### Topic association

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#### European Reference Networks - Events (16)



Showing results 1 to 16

TOPIC ASSOCIATION [Webinars of the COVID-19 Clinical Management Support System](#)

- 03 SEP 2020** PARTNER MEETINGS  
**Urology in the COVID-19 era**
- 23 JUN 2020** PARTNER MEETINGS  
**COVID-19 and Transplantation in Children**
- 15 JUN 2020** PARTNER MEETINGS  
**COVID-19 and Rare Connective Tissue and Musculoskeletal diseases and conditions**
- 11 JUN 2020** PARTNER MEETINGS  
**Second Wave of COVID-19: Preparatory actions - Consultation with Clinicians**
- 09 JUN 2020** PARTNER MEETINGS  
**The impact of COVID 19 for people living with a Rare Disease**

# Activities beyond MS expectations

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- » Acute and self-initiated responses to health crises (supported by the European Commission)
- » **Support of the Ukraine** after the beginning of the Russian war against UA
  - » **Immediate** reaction
  - » **High level of activity**
  - » Example slides from the ERN coordinators group (courtesy of Helene Dolfuss, ERN Eye)

# European Reference Networks & UA Crisis

- Immediate global solidarity for Rare Diseases patients :

ERN-CG & ERNs with EC, EURORDIS & EU & UA patient groups, ORPHANET , Learned Societies & Foundations, ECHO, CMHI, WHO, NGOs, ...

**HOW CAN ERNs SUPPORT RARE DISEASES PATIENTS from Ukraine ?**

**What are the needs ? How can ERNs support rare diseases patients ?**



## NEEDS



- **DIAGNOSIS:** elaboration – confirmation
- **URGENT & MAJOR THERAPIES:** rare cancer, dialysis, ...
- **SURGERY highly specialized:** transplantations, ...
- **THERAPY ADAPTATION / GUIDANCE:** epilepsies,...
- **MEDICAL EQUIPEMENT:** prothesis, ...
- **SPECIFIC DIETS:** metabolic diseases,...
- **« PSYCHO » Support:** intellectual disability patients, ...
- **DRUG ACCESS UNEVEN** in the UE : orphan & common

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## NEEDS



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# Future challenges and perspectives

» Let's talk about numbers

» Percentage Italian FM<sup>1)</sup> compared to all EU MS

	FM all MS	FM Italy	% all	FM Austria	% all <sup>2)</sup>
2017	846	189	22,3	2	0,2
2022	620	154	24,8	6	1,1
Total	1466	343	23,4	8	0,6

<sup>1)</sup> FM: Full member

<sup>2)</sup> Austria has currently further 41 ANC (Associated National Centres)



# Future challenges and perspectives

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» Let's talk about numbers

» Percentage Italian ERN–Eye FM<sup>1)</sup> compared to all MS

	FM total	FM Italy	% all
2017	28	6	21,4
2022	28	4	14,3
Total	56	10	17,9

<sup>1)</sup> FM: Full member

# Future challenges and perspectives

» Let's talk about numbers

» Comparison of the ratio of inhabitants to FM<sup>1)</sup>

	Inhabitants (million)	ERN FM	Inhabitants per FM	Projection EU (174.636/FM)
EU	447.7	1 466	305.389	2564
Italy	59.9	343	174.636	

<sup>1)</sup> FM: Full member

# Future challenges and perspectives

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- » Let's think about the numbers
  - » The Italian numbers are not a bad thing per se, there are “Pros” and Cons”
  - » Pros:
    - » Well developed centre system in Italy
    - » High level of interest from experts
    - » High pressure on Health Authorities from experts
    - » One aspect is recognition and prestige of experts
  - » Cons:
    - » **Rhetorical questions:**
      - » Are ERNs with > 2500 members **sustainable**?
      - » Are ERNs with > 2500 members **operational** (think of governance, funding, monitoring, evaluation, etc.)?

# Future challenges and perspectives

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## » Let's think about the numbers

» The Italian numbers are not a bad thing per se, there are “P”

We don't want to loose this kind of engagement

## » Pros:

» Well developed centre system in Italy

» High level of interest from experts

» High pressure on Health Authorities from experts

» One aspect is to create more experts

We don't want to create any unjustified frustration

## » Cons:

» Rhetorical questions:

» Are ERNs with > 2500 members sustainable?

» Are ERNs with > 2500 members operational (think of governance, funding, monitoring, evaluation, etc.)?

# Future challenges and perspectives

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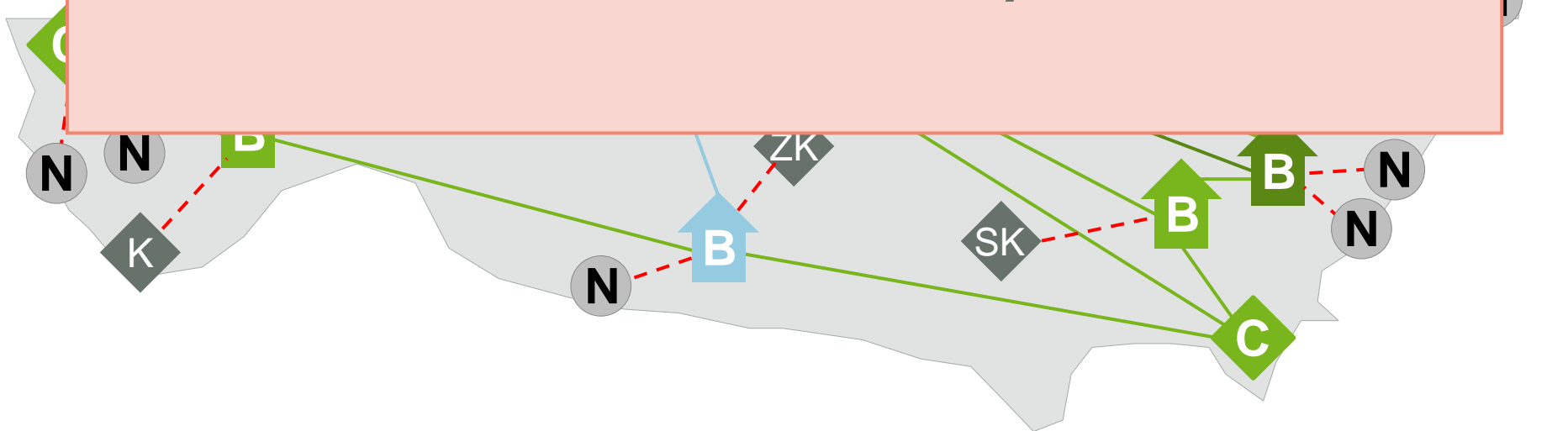
- » Challenge:
  - » How to keep the experts in the system while simultaneously reducing the size of the ERNs?
- » One potential solution:
  - » Creation of **National Reference Networks** (NRNs) adopting the example of ERNs on the national level
- » Rhetorical questions:
  - » Are ERNs with > 2500 members sustainable?
  - » Are ERNs with > 2500 members operational (think of governance, funding, monitoring, evaluation, etc.)?



# NRNs – first conceptual thoughts

Related ERN

» Better integration of ERNs into national healthcare systems



# Joint action on integration

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## Working areas

- » **Governance framework for national integration**
  - » National reference networks
  - » National coordination office for the integration
  - » National data governance models
- » **Patient care pathways**
  - » Adoption/Adaption ERN Clinical Practice Guidelines
- » **Referral systems** to ERNs
- » Education and **national awareness raising** on ERNs
- » **Sustainability** of the ERN model **at the national level**

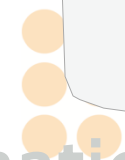


# Summary

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# ERN-Konzept in der Computereinführung



[http://ec.europa.eu/health/ern/board\\_member\\_states/index\\_en.htm](http://ec.europa.eu/health/ern/board_member_states/index_en.htm)

[till.voigtlaender@meduniwien.ac.at](mailto:till.voigtlaender@meduniwien.ac.at)

