



EUROPEAN REFERENCE NETWORKS UPDATE – 9.45-10.45

**ERN 4TH ANNUAL CONFERENCE AND
INTEGRATION OF ERNS INTO NATIONAL
HEALTH SYSTEMS**

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 - Joint Strategy on ERNs – ePAGs, National Alliances and European Federations



1. Outcome of ERN 4th Annual Conference

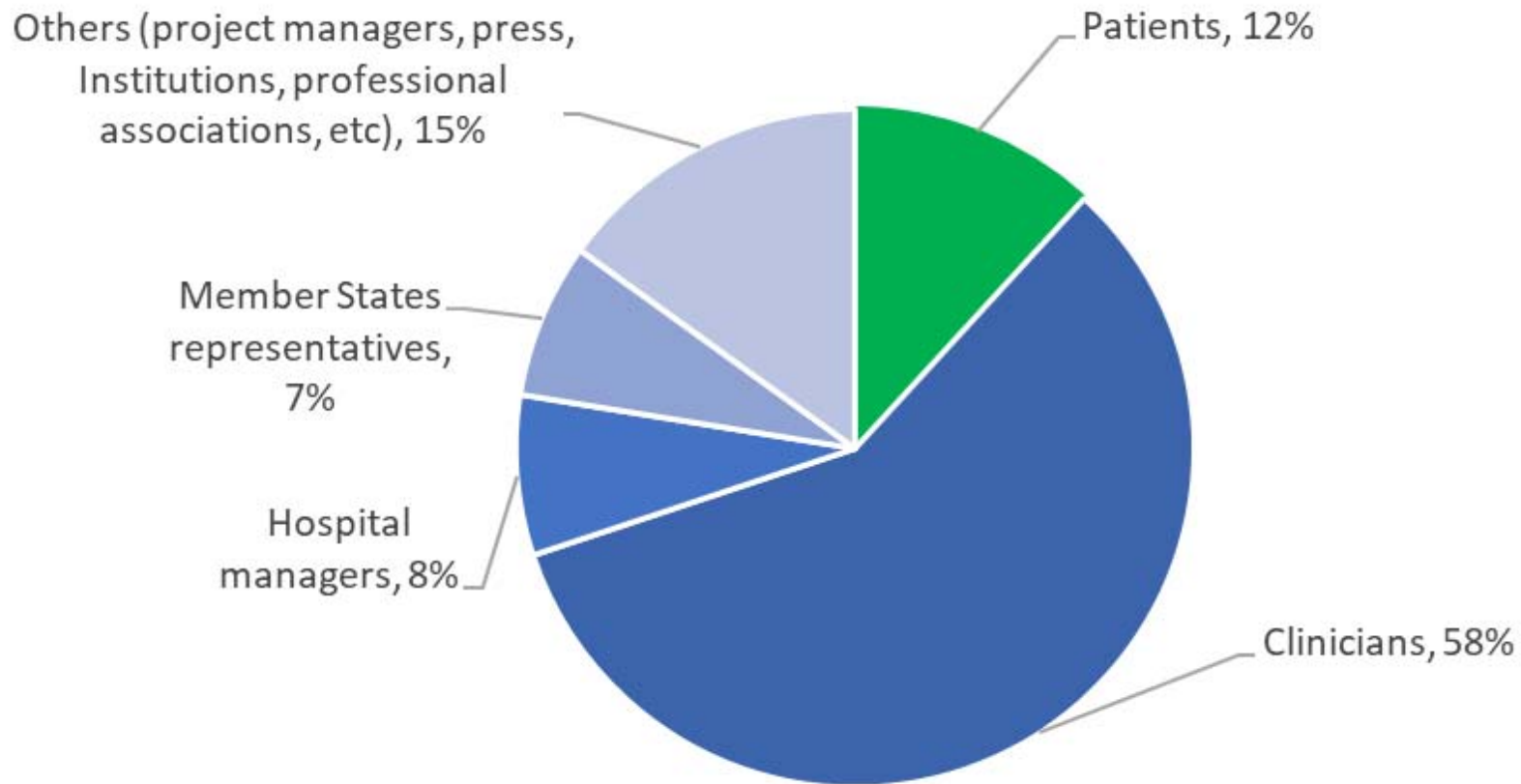
1. Attendance



432 participants, 51 patient representatives

2. Attendance - breakout by stakeholder

Attendance breakout by stakeholder - ERN Conference 2018



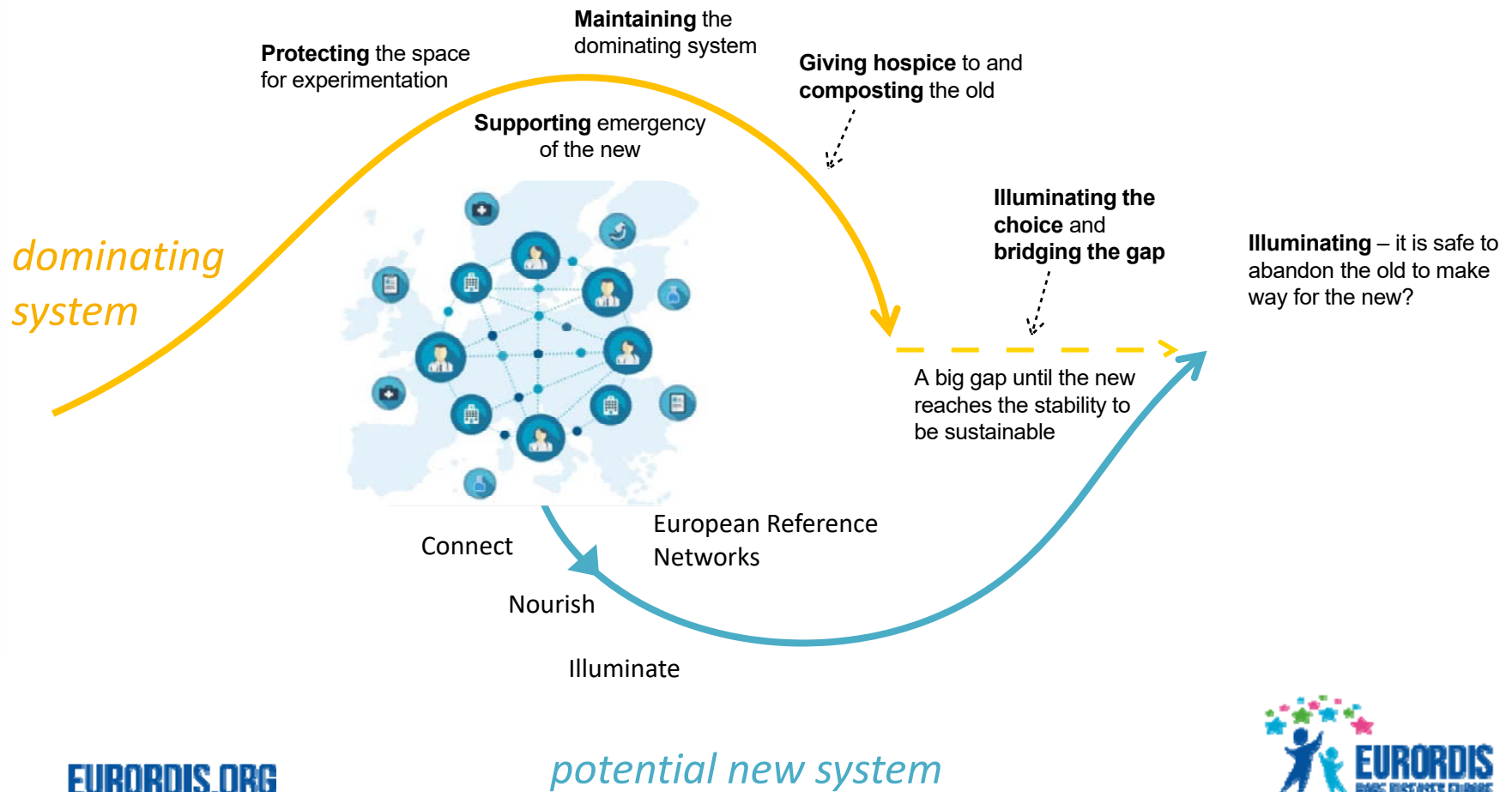
2. Conference Key topics

1. **Enlargement and coverage:** Improving the geographic and disease coverage of the networks was a recurring theme. Tension between need to enlarge ERNS while maintaining the quality of ERNs and avoiding operational challenges. What is the ideal number of HCPs per country?
2. **Integration of ERNs** into national health systems and the need for MS to steer this process and take ownership
3. **Funding** and long term financial planning. We need to have a long term financial strategy – funds coming from different funding mechanisms – industry, included (framework under preparation)
4. **Raising awareness at national level**
5. **CPMS** - Coordinators' had 2 main requests - reimbursement of consultations (proposal –solidarity fund) AND virtual advise needs to be recognised as a high quality and state of the art intervention across Europe.

3. Main challenges for the future – Paradigm Shift (1/3)

Berkana Institute
Two-Loop model

A system is inclined to self preservation.



4. Main challenges for the future (2/3)

Goal: Consolidate Networks and coordinate their expansion to ensure balance representation of experts & proportional coverage of MS

- ▶ Safeguard against loss of key and valued leaders and expertise (Brexit).
- ▶ Limited and diminishing capacity due to heavy administrative burden.



- ▶ Only a few Members are really active.
- ▶ Lack of independent multi-stakeholder advisory body to provide strategic direction. Polyphony on strategic priorities, with each stakeholder pushing in different directions.
- ▶ Integration of ERNs into NHS through referral pathways & contractual relationships.
- ▶ Public confidence in Network expertise, quality control, safe-guarding patient safety.

5. Main challenges for the future (3/3)

- Keeping Networks manageable!
- Ability to manage Next Call for New Members of Existing Networks – Open vs. Restricted. No clear vision how ERNs should look like in 5, 10 or 20 yrs.
- Adoption of a common model for Network Member between MS.
- Alignment of MS endorsement of expertise under national laws.
- Multi-professional membership and inter-ERN collaboration.
- Defining rights and obligations of Full and Affiliated Members



6. Quality assessment, monitoring and evaluation of the networks – ERN 18 Indicators

Domain	Indicator
Coverage & Membership	<ol style="list-style-type: none"> 1. No. MS represented in the ERN as full HCP Members 2. No. of HCP Members 3. No. of Affiliated Partners (AP) represented in the ERN 4. No. of PO in the ERN Meetings
Expert Advice	<ol style="list-style-type: none"> 5. Total No. of New Patients referred to HCP Members 6. No. of Patients entered into CPMS (total volume) 7. No. of Panel Case Reviews 8. Delay to provide multidisciplinary clinical advice: Non-emergency cases
Patient Satisfaction	9. Level of patient satisfaction
Education Activities	<ol style="list-style-type: none"> 10. No. of Educational Webinars for healthcare professionals 11. No. of Formal Educational Activities for healthcare professionals
Research	<ol style="list-style-type: none"> 12. No. of Clinical Trials or Observational prospective studies within ERN 13. No. of Peer-Reviewed Publications in scientific journals
Clinical Guidelines	<ol style="list-style-type: none"> 14. No. of Clinical Practice Guidelines adopted 15. No. of new ERN Clinical Practice Guidelines 16. Health Care Provider Compliance to Clinical Guideline
Dissemination Knowledge	<ol style="list-style-type: none"> 17. No. of Congresses/Conferences/Meetings which the ERN activities and results were presented 18. No. of individual ERN website hits

7. Parallel Session on patient-clinician partnership

- ▶ It takes time to develop a partnership approach. It will not happen overnight, patient-clinician partnership needs to be nourished.
- ▶ Being part of a team means that patients have access to all information not only selected information.



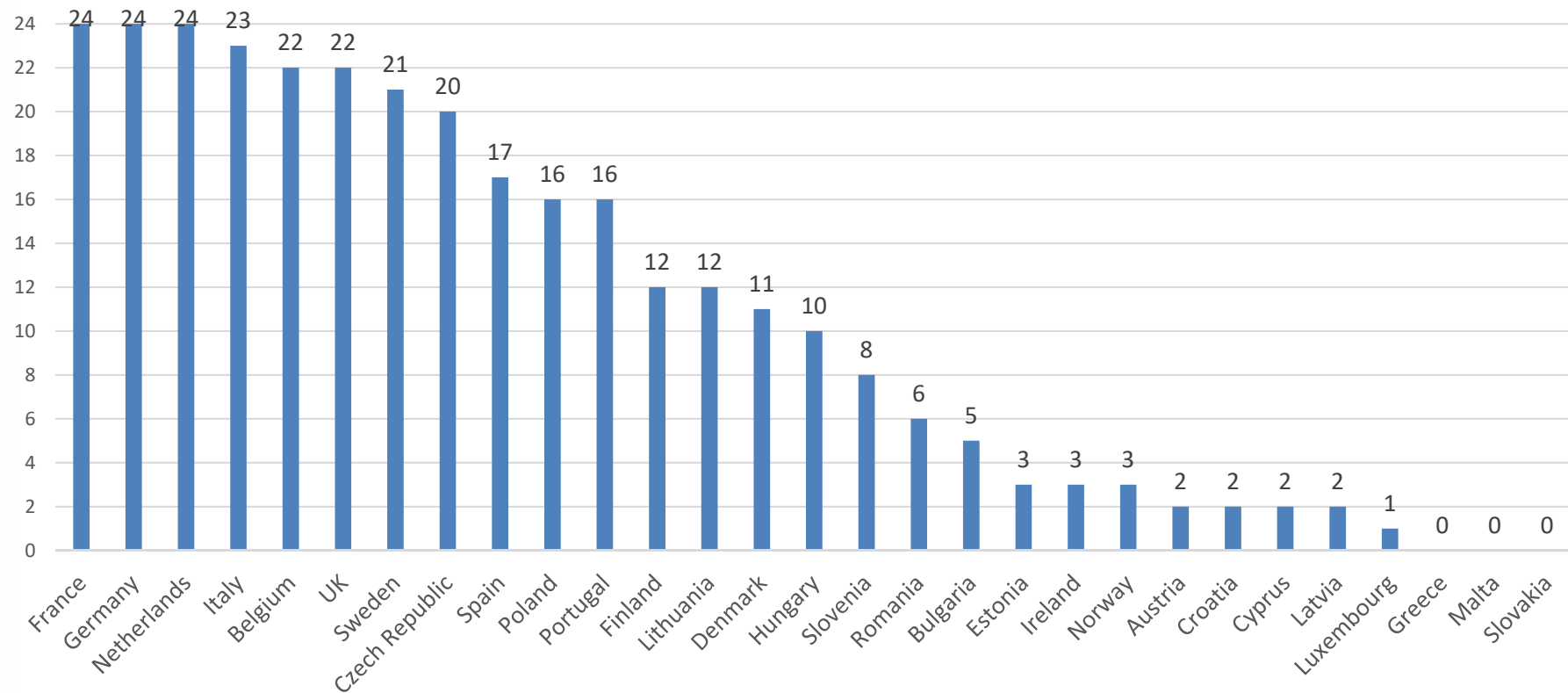
- ▶ Patients will be eager to contribute as long as they feel that their opinions are being heard and have an impact.
- ▶ We need to empower patients to develop confidence.
- ▶ Some patients may need training to see the bigger picture and some clinicians training on how to communicate with patients.



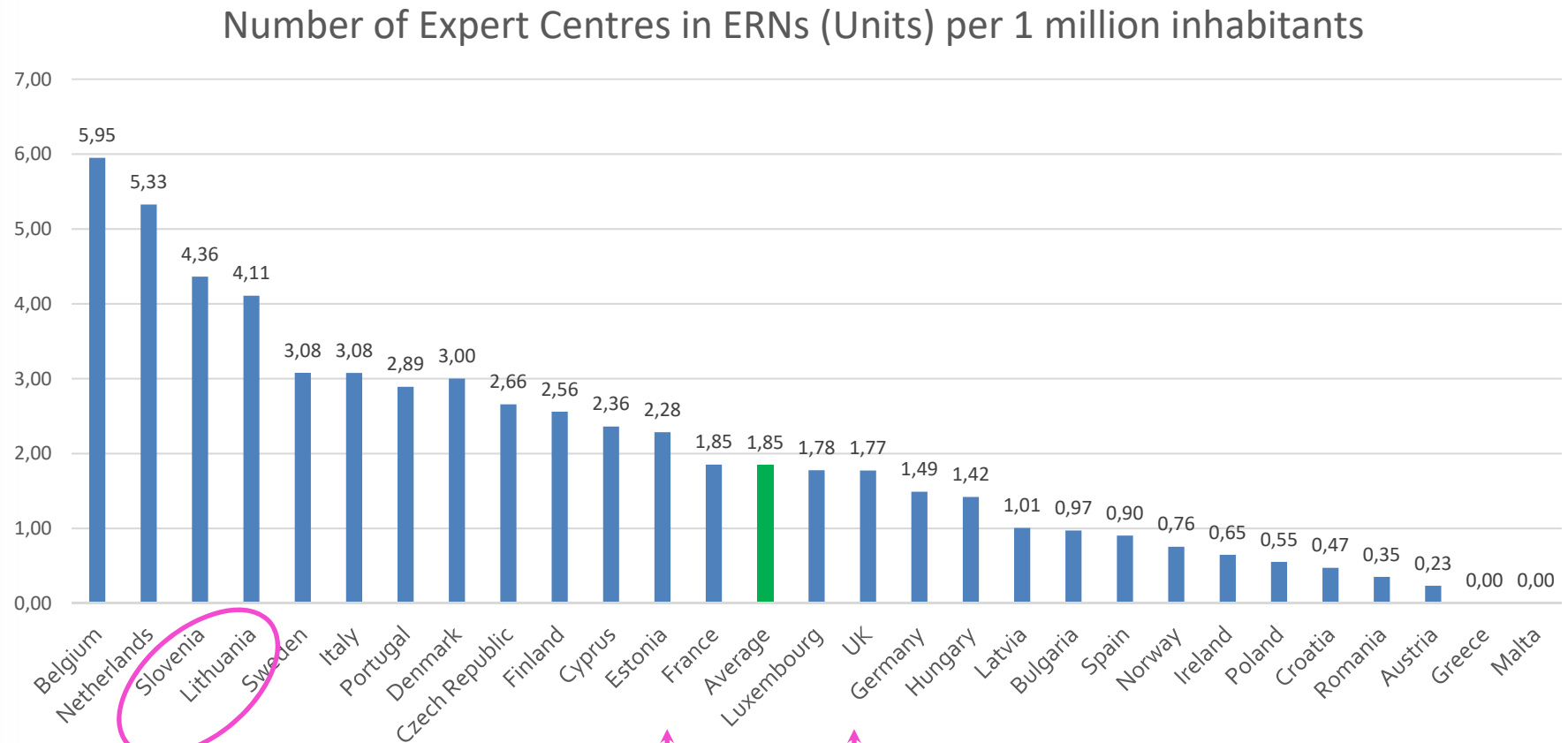


2. ERN Geographic and Disease Coverage – Where are we today?

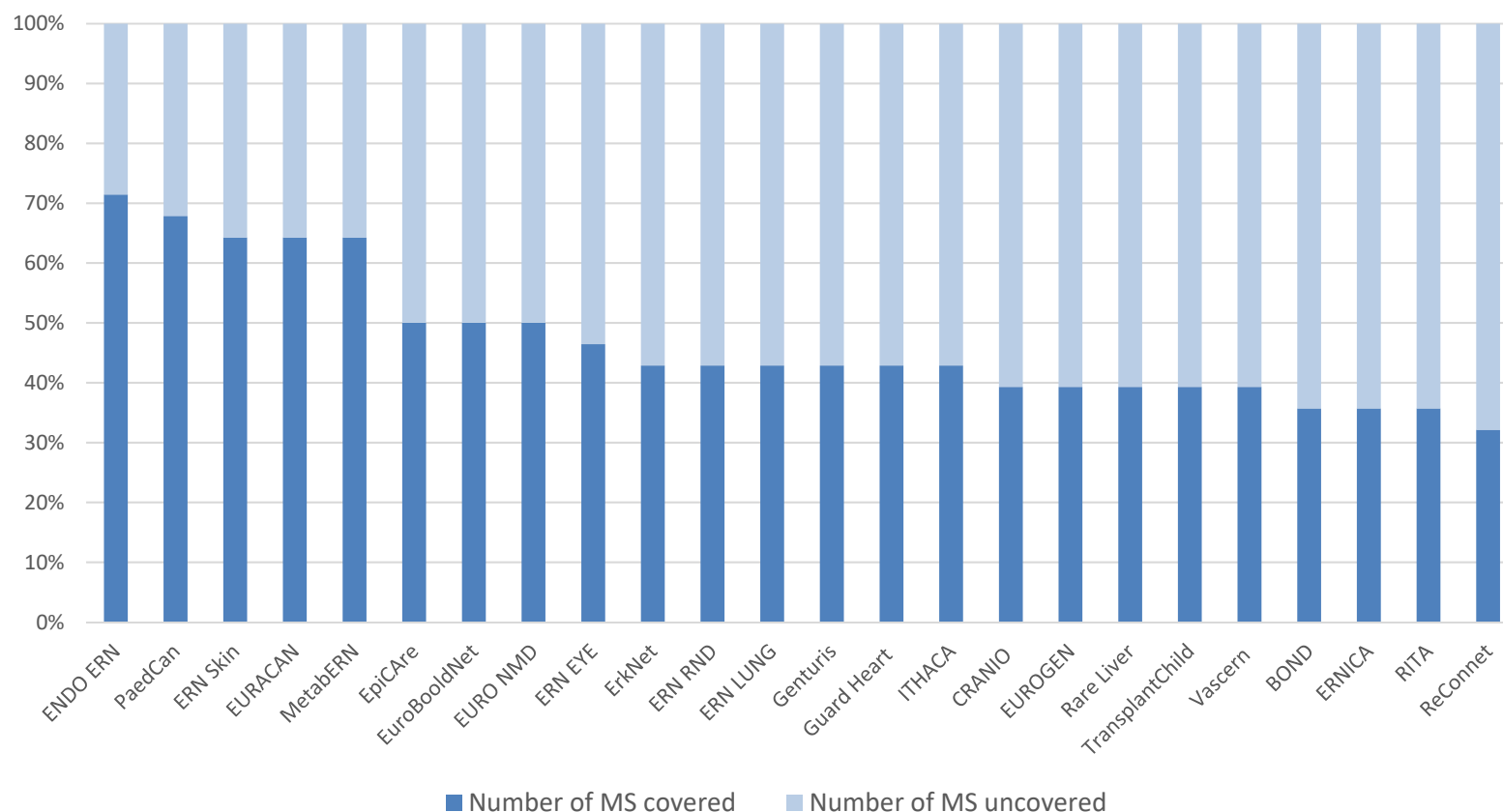
1. Coverage per MS - Number of ERNs where the MS has at least 1 expert centre (unit)



2. Coverage per MS – ERNs per 1 million inhabitants

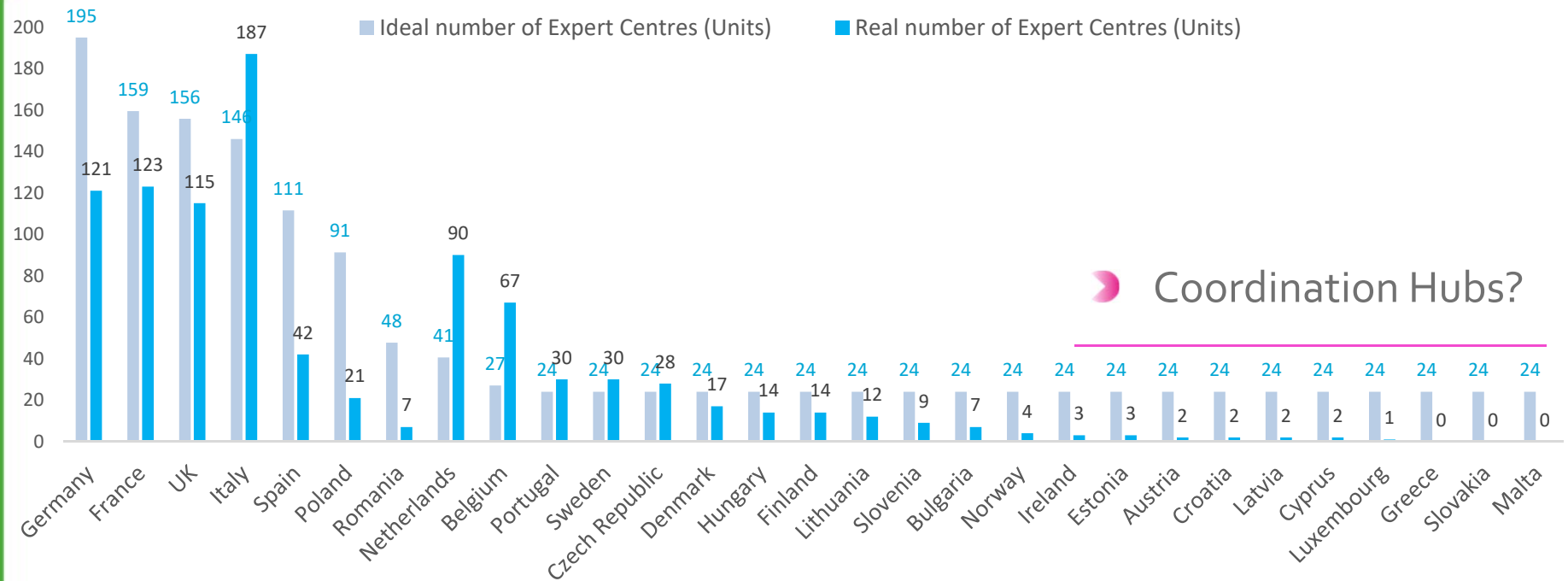


3. Number of countries represented in each ERN



- 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

4. 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 (around 1,400 centres in total)

5. Disease coverage

- ▶ Disease coverage per ERN - information is not publicly available. EC and Coordinators are working on a database to collect this info. Latest info available is from 2016 - ERNs applications.
- ▶ ERN Coordinators report 60% of Rare Diseases are covered in the ERNs but this is anecdotal
- ▶ We know that some ERNs are focusing only in a small number of diseases (as few as two)
- ▶ No network is actively developing or implementing an expansion plan of their network's scope
- ▶ EC & ERN BoMS recognize there are some gaps in ERN coverage and had previously indicated there would be a second Call for new ERNs e.g.: rare diseases that occur during pregnancy; or for highly specialized interventions. However this has not been referred since the launch of 24 ERNs

6. Timeline

- Affiliated partners - Dec 2018 - Spring 2018
 - MS to designate affiliated expert centres by Spring 2018, some have already completed this process (MS competency).
 - ERN Coordinators to develop their integration strategies to integrate the new affiliated partners
 - Coordination Hubs? Different timing?

- Call for new members - estimated, Spring/Summer 2019?



2. Integration of ERNs into national health systems

- Why is this topic relevant?
- EURORDIS Recommendations
- Number of ePAGs per Country and ERN
- Joint Strategy – ePAGs, NA and European Federations

1. Why is this topic relevant?

- ▶ ERN model today relies on voluntary cooperation, but its potential will only be fully realised if ERNs are supported at national level, to ensure that the **knowledge and innovations generated are implemented, accessible and support the national healthcare system.**
- ▶ **Joint WG BoMS + Coordinators on Integration.** Focusing now is on exchanging best practices on referrals/patient pathways.
- ▶ **EURORDIS Recommendations**
 - 10 Recommendations that go beyond ensuring access to virtual consultations and look into the measures needed to ensure that knowledge produced or pooled by the ERNs reaches the national level.
 - Organised in 2 big areas of action: policy/macro level and more specific targeted actions
 - **Coordinators Network Group** discussed the paper in their meeting on the 20th Nov, agreed with its content and Coordinators will use it.

2. EURORDIS Recommendations (macro level)



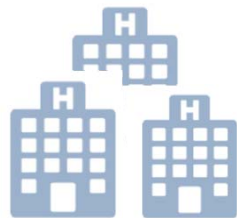
Create a good level of awareness at national level on ERNs



Ensure political leadership and ownership of the ERN system at national level and generate sound evidence on the value of the ERN model



Review or adapt national policies on rare diseases to address integration of ERNs into the national health systems (RD National Plans)



MS to set up national networks of rare disease expert centres and the RD patient community to create national networks compatible with the ERN-disease groupings.

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2. EURORDIS Recommendations (micro level)



Incorporate new Full Members and Affiliated Partners specifically to cover ERNs geographical and/or expertise gaps



Set up National Coordination Hubs and designate ERNs national focal points



Streamline the process to endorse healthcare providers that apply for full membership



Define and validate ERN referral pathway at national level to ensure timely access to ERNs advice and adequate management of case referrals

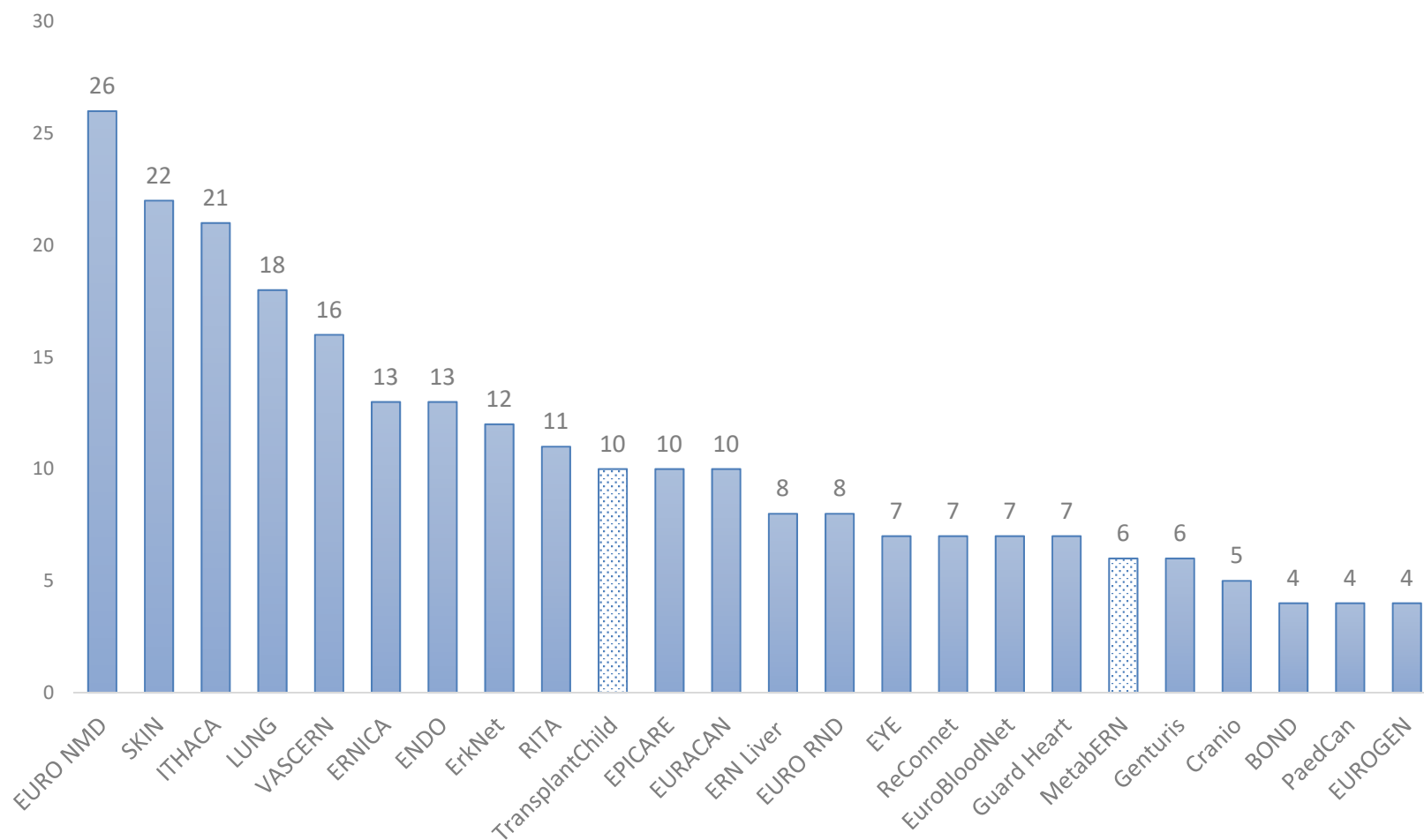


Establish a clear funding mechanism for ERNs virtual consultations



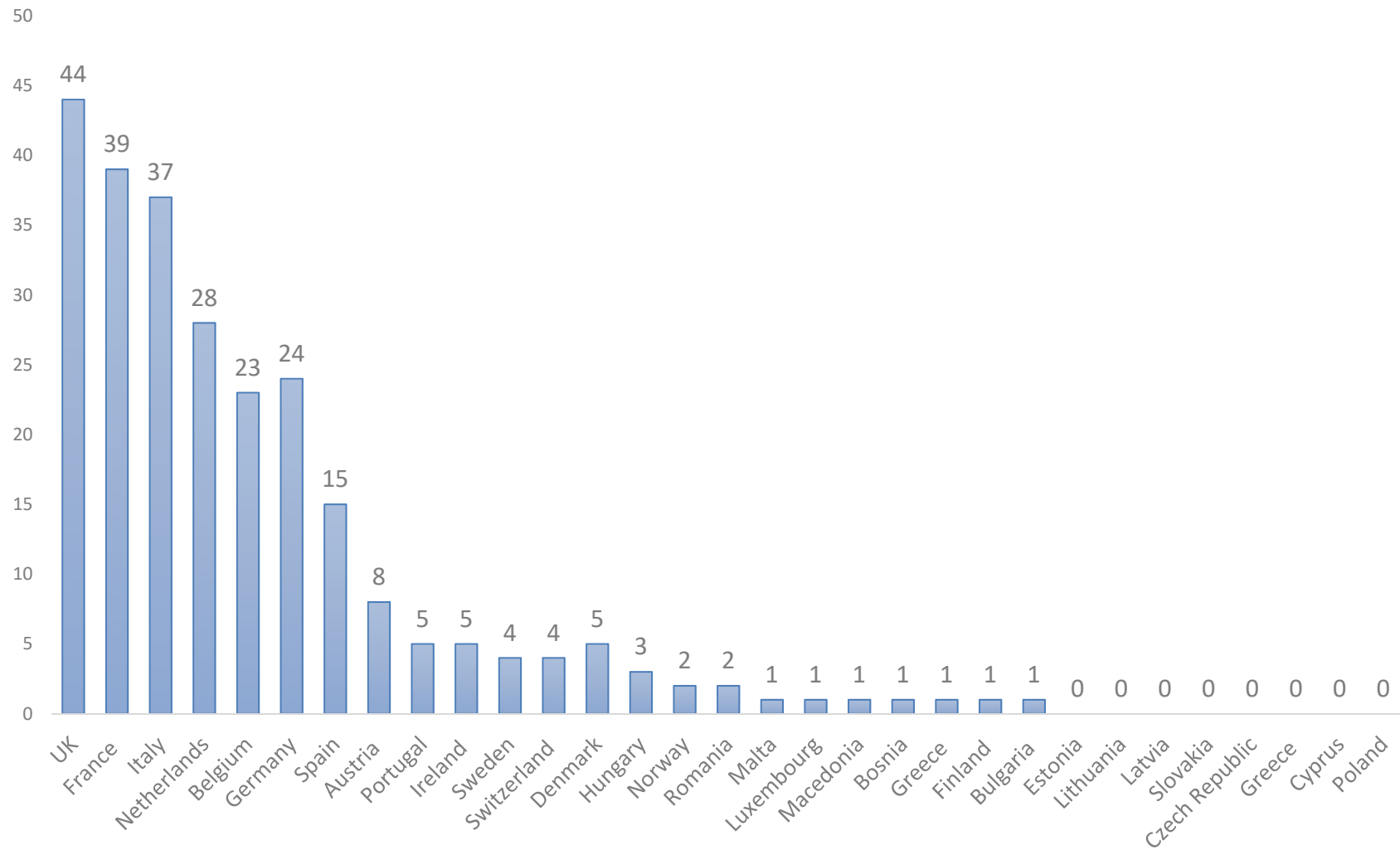
Develop a mechanism to recognise and adopt at national level clinical guidelines reviewed or adopted by ERNs

3. ePAG Patient Advocates per ERN



Note: MetabERN and TransplantChild are updating their information, so the number of patients involved in these ERNs might be larger.

3. Number of ePAG Patient Advocates per Country



4. EURORDIS Recommendations – Joint Strategy (1/6)

1. RAISE AWARENESS - ACTIONS	ePAGs	NA	European Feds.
Engage with the MoH and regional health authorities to disseminate and raise awareness of ERNs -organise national conference/meeting on ERNs.			
Engage with Scientific Societies at national level to explain ERNs value and concept.			
Liaise with Scientific Societies at European level to explain ERNs value and concept.			
Engage with the representatives of the national patient RD community to explain the ERN model and patients' involvement in ERNs.			
Engage with clinicians and HCPs at local level , including hospital managers on ERNs to explain the ERN model and what's in it for them.			

4. EURORDIS Recommendations – Joint Strategy (2/6)

2. ENSURE POLITICAL LEADERSHIP AND OWNERSHIP AT NATIONAL LEVEL - ACTIONS

ePAGs

NA

European
Feds.

Guide MoH and regions on **sources of funding/EU structural funds**. Support them to steer the process leading to the definition of national priorities (Operational Programmes, structural funds)

Encourage/support MoH to **identify and capture their demand for ERN services**

Engage with the MoH in **identifying the indicators to measure impact of ERNs at national level** - include them into the national health system performance measurement mechanism

4. EURORDIS Recommendations – Joint Strategy (3/6)

3. REVIEW OR ADAPT NATIONAL RD POLICIES ACTIONS

ePAGs NA European
Feds.

Engage with MoH to adapt or review the RD National Plan in order to integrate ERNs into the national health system structure: address the need to **build technical capacities, as well as the organisational and legal reforms** required to anchor ERNs into their national health and social care systems - to facilitate broad dissemination/uptake of knowledge and expertise.

Liaise with MoH/regional health authorities to **align their accreditation criteria for centres of expertise with the operational criteria for ERN full members.**

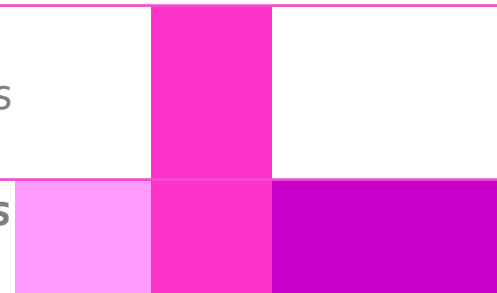
4. EURORDIS Recommendations – Joint Strategy (4/6)

4. CREATE NATIONAL NETWORKS OF CENTRES AND PO - ACTIONS

ePAGs NA European Feds.

Drive the creation of national networks of centres of expertise in coordination with national expert centres, clinicians and MoH/regional health authorities

Encourage the rare disease patient community to work across disease areas and demonstrate value of this approach



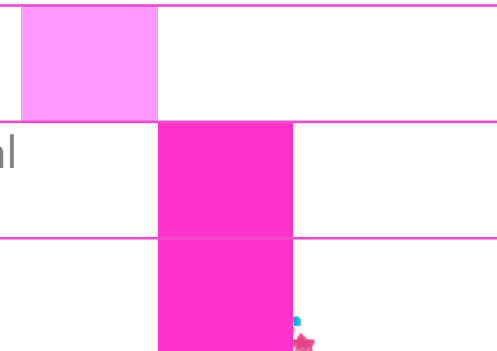
5. MANAGE ENLARGEMENT PROCESS TO COVER GAPS ACTIONS

ePAGs NA European Feds.

Liaise with ERN Coordinators – to understand what are the ERN disease/geographic coverage plans

Engage with MoH, expert centres, HCPs managers, and regional health authorities to perform gap analysis

Understand and discuss with the MoH their strategy towards affiliated / full membership



4. EURORDIS Recommendations – Joint Strategy (5/6)

	ePAGs	NA	European Feds.
6. SET UP COORDINATION HUBS AND IDENTIFY ERNS NATIONAL CONTACT POINTS - ACTIONS			
Define together with the MoH the role and functions of National Coordination Hubs			
Help identify the HCPs that could play the role of national focal point role (per ERN).			
7. STREAMLINE ENDORSEMENT PROCESS FOR HCPs – ACTIONS			
Engage with the MoH to understand how it plans to develop its endorsement process for the new call			
Monitor the endorsement process for full members to ensure that it is timely and transparent			

4. EURORDIS Recommendations – Joint Strategy (6/6)

	ePAGs	NA	European Feds.
8. DEFINE AND VALIDATE ERN REFERRAL PATHWAY - ACTIONS			
Engage with ePAGs to inform/train them current situation regarding the organisation of care for RD, RD pathways and good practices at national level.			
Work with the MoH and clinicians at national level to define and validate ERN referral pathways			
Review/amend current RD referral pathways where needed			
Disseminate ERNs referral pathways when adopted			
10. DEVELOP A MECHANISM TO RECOGNISE AND ADOPT AT NATIONAL LEVEL CLINICAL ERN GUIDELINES - ACTIONS			
Advise the MoH on the adoption of guidelines at national level and monitor adoption			
Monitor the adoption of ERN guidelines at European level			

5. EURORDIS support to NA on ERNs

1. F2F workshops on ERNs with NA

- In 2018 we have supported the following NA: DE, PO, SP, UK, RO, AT,CRO, IE, GR, SW, FR, ES.
- Different format, depending on NA needs (some with the participation of clinicians, reps of ministry of health, or only patients).
- Scheduled/planned for 2019: The Netherlands, Denmark, Spain, Cyprus, Germany, Italy. What are the needs?

2. Organise dedicated calls to share what each NA is doing, discuss progress and exchange good practices with others

Thank You

