



European **Rare Diseases**
Research Alliance

The role of **National Mirror Groups – NMGs**

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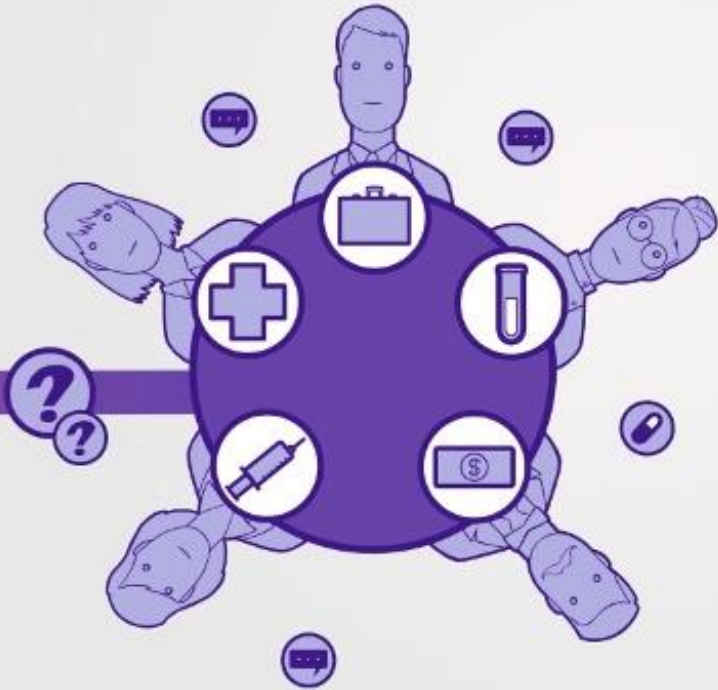


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NATIONAL MIRROR GROUPS (NMGs)

Objective of the NMGs in European Joint Programme on Rare Diseases (EJP RD)

The role of the NMGs will be to ensure national coordination of and with all rare diseases stakeholders to facilitate the alignment between national and EJP RD activities, to contribute to the objectives of the EJP RD and benefit from it.

NB – Can be an existing or new group/body: and can be mostly research-focused or look at broader RD issues.

NMGs: Composition

Guidelines/ToR EJP RD: Although the creation and composition of a NMG is at the discretion of each participating country, it is recommended to involve the following stakeholders

- EJP RD Governing Board representative
- EJP RD Policy Board representative(s)
- National partners working in EJP RD
- Relevant national authorities (Ministry of Health, Ministry of Research, etc.)
- Representatives of the National plan/strategy for rare diseases
- **European Reference Networks members**
- Research institutions involved in RD research (participating to the EJP RD or not)
- **Representatives of patient organisations**
- Representative of Orphanet local teams



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The role of NMGs in ERDERA

- To help bridge the gap between the European/International RD level, on the one hand, and national RD level on the other: effectively, this means
 - Channeling national needs, realities and good practices into ERDERA, to help shape its activities
 - Optimise the dissemination, the implementation and use of the outputs and lessons of ERDERA into the national landscape
 - Avoid duplication of efforts on national and international level
- NMGs will enable more focused interactions and good practice sharing *between* countries
- National Alignment Board (representatives NMGs and EC services) advises ERDERA on the implementation of best practices

NMG – examples of planned ERDERA activities

National Meetings & Dissemination:

Local/national meetings with full NMG for exchange
Dissemination of outputs of ERDERA
Collection of data on national level for e.g. surveys

NMG Leads' Meetings/Interactions:

Once a year to learn about the NMG needs, activities, realities

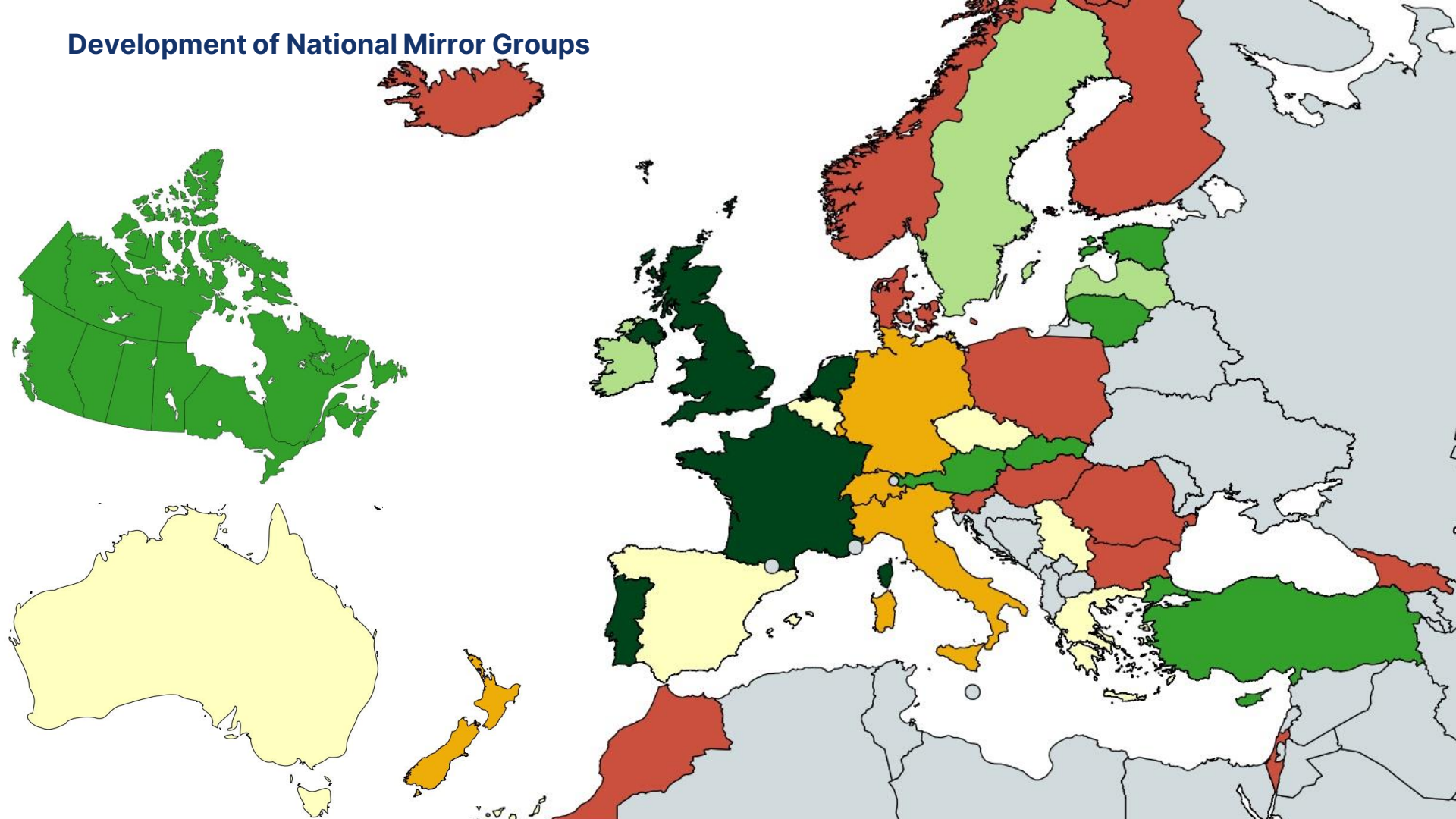
NMG

Support 'Train the Trainer' activity
Sharing info on national training needs

Annual Topic Workshops

Intention to share good/innovative practices, generate new knowledge, explore ERDERA advice, and optimise synergies for greater alignment

Development of National Mirror Groups



Example #1

The development of the Lithuanian group



Creation of the NMG Lithuania in 2021

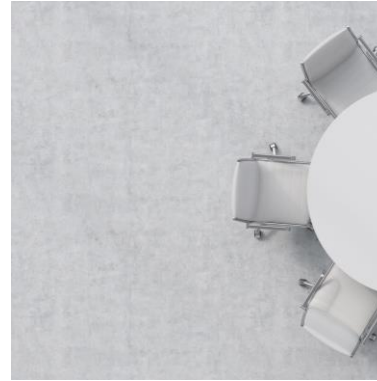
Steps



EJP RD guidelines was used



E-mail was send to the identified stakeholders' administrations



Organised a first meeting in the end of 2021



Keeping communication by e-mails

Activities

Content of regular meetings (quite informal!) at least once a year

discussions on participation in EJP RD and ERDERA

meetings with EJP RD and ERDERA Coordination

contribution to LT policies and surveys of EJP RD

perceived challenges and drivers for participation

sharing information and awareness-raising

Main features

Composition and the status

The creation was initiated by the EJP RD beneficiary institutions (Research Council of Lithuania and Vilnius university hospital Santaros Clinics) representatives based on the recommendations of EJP RD. The group is not formalized and function on voluntary basis. The most important aim since the start was **creation of the community and building interinstitutional and personal trust.**

Current status / Composition

- Clinicians (from university hospitals, **members of ERNs**)
- Policy makers (Ministry of Health)
- Researchers (from universities)
- Funder representative
- ECRs

Future plans

1. Strengthen administration capacities
2. Include new members (especially representatives of PAOs)
3. Widen the portfolio of activities.

Example #2

The development of the Dutch NMG



Dutch NMG - composition

Mix of expertise, representation and commitment to effectively align national RD research efforts with goals

- Started NMG with a small group in May 2019 that was extended in 2019/2020 to 23 people
- The Dutch representative in the EJP RD Governing Board is chair
- Dutch partners in EJP RD (researchers, clinicians, research funder)
- Dutch ERN coordinators**
 - Coordinator Orphanet NL/coordinator of Dutch Centers of Expertise
 - Dutch Federation of University Medical Centers
 - Umbrella patient organisation for genetic and rare diseases**
 - Dutch ePAG representative**
 - National Health Care Institute
 - Ministry of Health

Dutch NMG - activities in EJP RD



Meetings

- 🌈 Full NMG: face-to-face or online; quite informal
- 🌈 Small subgroups: face-to-face or online

Activities such as discussing

- 🌈 Annual Work Plans EJP RD
- 🌈 Use cases for input national policy letter and for Dutch/European activities
- 🌈 Input for EJP RD surveys or for patient alliance survey on national plan/national strategies
- 🌈 Rare disease community representation in Health-RI (Dutch national data infrastructure)
- 🌈 Sharing information on EJP RD and preparing/joining ERDERA
- 🌈 Input for Strategic Research and Innovation Agenda for ERDERA
- 🌈 Bi-weekly meeting of subgroup on JARDIN activities (from March 2024)

Restart/restructuring the Dutch NMG for sustainability

The primary objectives of the NMG will be kept; new NMG members may be added

NMG: CIRCLE OF ACTIVITIES

Feed national needs and expertise into ERDERA's activities



Facilitate collaboration between national stakeholders in the field of rare diseases



Disseminate ERDERA's outcomes at national level



Facilitate uptake of ERDERA outcomes on national level

EXAMPLE



Proposal to be discussed in Dutch NMG in January 2025

NMG working on key areas managed by **dedicated portfolio working groups**

Plan

Develop 5-year plan aligned with ERDERA's roadmap

Focus

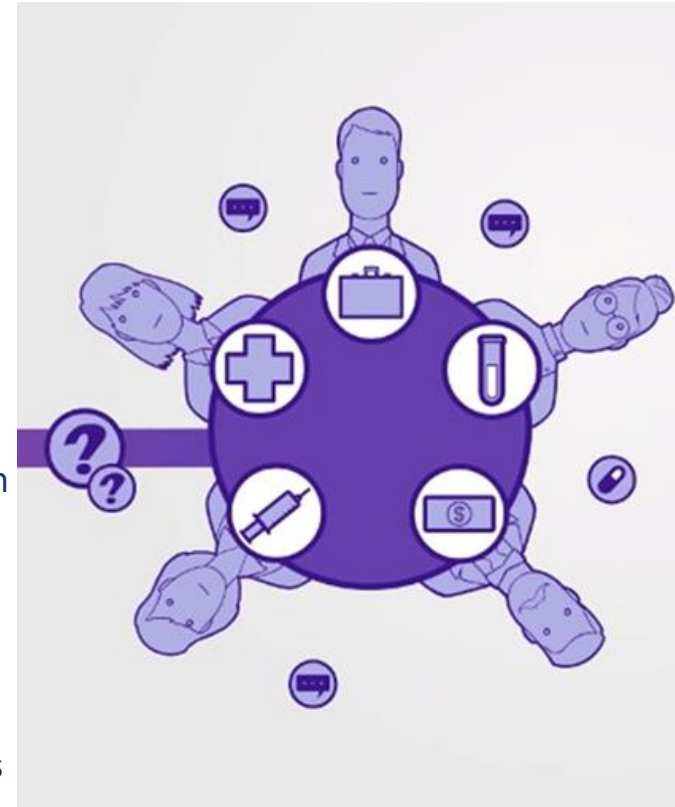
ERDERA key areas are leading, each managed by dedicated portfolio.
Starting with a few portfolios and extending in time

Portfolio

Specific measurable aims to be defined with defined timeframes

In conclusion

- Many countries have developed or are developing NMGs
- ERDERA coordination helps in developing NMGs
- The way of creation and the composition of a NMG can be different in each country
 - Involving coordinators and members of ERNs is an added-value
 - Involve PAOs and patient representatives as patient-led research is needed
- NMGs can create national RD community and build interinstitutional and personal trust
- NMGs can share and align national and international RD information and good practices and avoid duplication of efforts





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Thank you for your attention!



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