Rare Diseases National Mirror Groups
NMG: Objective and Role

Coordinate the participation of national actors in the field of RD into the EJP RD activities

Define the national position and priorities to be reported to the EJP RD and for its Annual Work Plan

Ensure the alignment between EJP RD and national strategy in the field RD by promoting EJP RD actions and outcomes at national level

⇒ 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
NMG: Composition and Organisation

- EJP RD Governing Board representative
- EJP RD Policy Board representative(s)
- Representative of Orphanet local teams
- Relevant national partners of the EJP RD
- Relevant national authorities (i.e., representatives of the ministry of Health, ministry of Research, etc.)
- European Reference Networks members
- Representatives of patient organisations
- Research institution involved in RD research (participating to the EJP RD or not)
- Representatives of the National plan/strategy for rare diseases
- At least 1 face-to-face meeting per year: ideally in June to discuss the Annual Work Plan
- If relevant, creation of Working groups
Rare Diseases National Mirror Groups example of FRANCE
French National Mirror Group

- Set up in May 2019 in the joint context of EJP RD and the French National Plan for Rare Diseases 3 (PNMR3)

Missions of the FR NMG:

- Coordinate the participation of rare diseases French community to EJP RD activities
- Sustain the setup of consortia, through the ‘Filières’, for the submission of collaborative projects to international and European call for projects
- Be pro-active to ensure the fluidity of clinical research until basic research to return to the patient
French National Mirror Group

Composition:
- Representatives of Research institutions involved in RD research: Inserm (Aviesan), APHP
- Representatives of national authorities: ‘Direction Générale de la Recherche et Innovation (DGRI)’ and ‘Direction Générale de l'Offre de Soins’ (DGOS)
- National partners of the EJP RD: Orphanet, IMAGINE, FFRD, RaDiCo, EURORDIS, AFM, ANR, ERNs
- Alliance Maladies Rares (national alliance of RD patient organisations)
- Representatives of Filières Santé Maladies Rares (French RD centers of reference)

Animated by EJP RD coordinator and DGRI and chaired by Pr Elisabeth Tournier-Lasserre, research vice-chair of the PNMR3

4 meetings per year

- March
- June
- September
- December

Presentation and discussion of the EJP RD annual Work Plan

Presentation of results of French community in call for projects during the year
Close collaboration with national stakeholders spanning beyond EJP RD partners

Possibility to consult FR community in advance and establish FR position as well as collect needs

Connection between EJP RD and national activities (RD National Plan, other initiatives e.g. Plan France Genomics 2025) allowing true impact (e.g. integration of EJP RD developed standards in FR databases; building FR scientific community in response to specific calls, etc.)

Expanded support for national community, e.g. request to adapt EJP RD Helpdesk to accept demands in national languages or produce communication materials in national language
French National Mirror Group
Benefits & challenges

CHALLENGES:

- Keeping multiple (busy) stakeholders on board → can be solved by good organisation and scoping of meetings & actions of NMG
- Good balance between national position/recommendations and final decision at EU (EJP RD) level → requires clarity and transparency on the decision making process and role of the NMG
- Alignment of agendas (national and EJP RD planning) and short deadlines for feedback (e.g. on Annual Work Plan)
Rare Diseases National Mirror Groups

PORTUGAL
In Portugal, the set up of the NMG started during 2019

First, the two EJP-RD Portuguese Members, INSA (National Health Institute of Health Dr. Ricardo Jorge) and FCT (Foundation for Science and Technology) agreed that a major partner which should be involved in the coordination of NMG was DGS (Directorate General for Health) that is also represented in the EJP-RD Policy Board and contacted DGS in that regard.

- Two face-to-face meetings have occurred (one in the end of 2019 and the other in the beginning of 2020) between representatives of these 3 institutions.
It was agreed that the Portuguese NMG will be coordinated by INSA in closer collaboration with FCT and DGS.

These three institutions also decided that other national relevant stakeholders in the rare diseases field will be contacted to participate in the NMG. In a first stage it is planned to contact:

- Portuguese Commission for the Reference Centers
- Portuguese rare disease patient organisation
- Orphanet Portugal

Due to the Covid-19 pandemic situation, those contacts were not yet established but as soon as possible those stakeholders will be contacted and a first meeting will be scheduled.