

# Rare Diseases National Mirror Groups

# NMG: Objective and Role

## National Mirror Groups

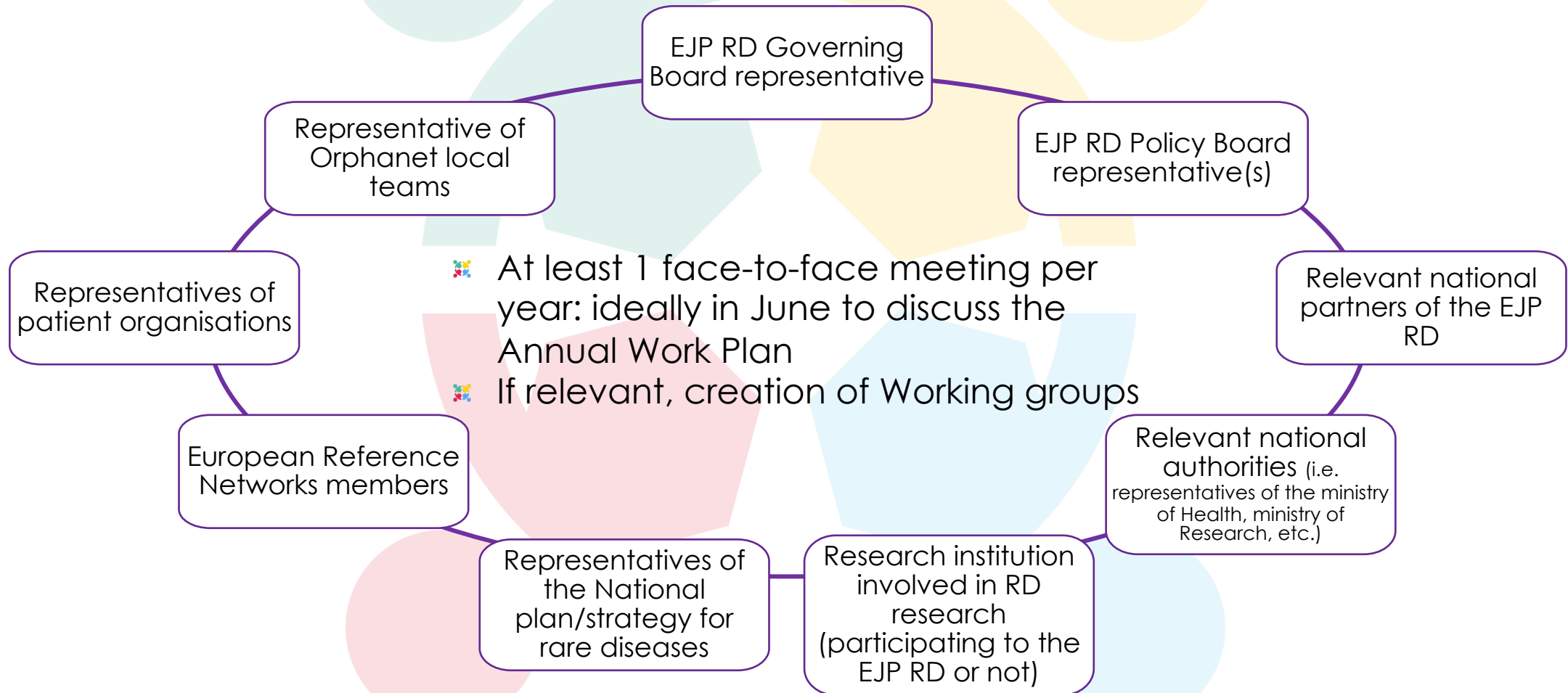
**Coordinate** the participation of **national actors** in the field of **RD** into the EJP RD activities

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



# 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)

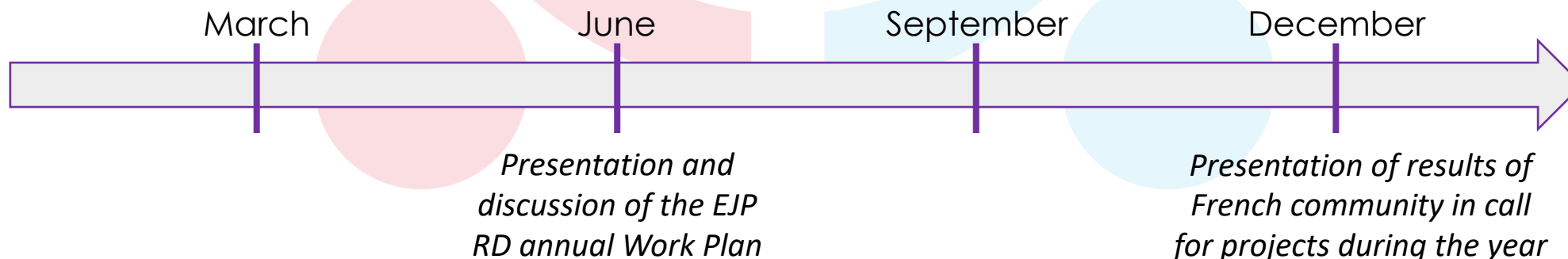
## Missions of the FR NMG:

- 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-Lasserve, research vice-chair of the PNMR3
- 4 meetings per year



# French National Mirror Group

## Benefits & challenges

### BENEFITS:

- 🌟 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

# National Mirror Group - 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.

# National Mirror Group - Portugal

- 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