

EJP RD National Mirror Groups










Terms of Reference

Objective of the National Mirror Groups (NMGs)

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.

Composition of the National Mirror Groups




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);
-  Relevant national partners of the EJP RD;
-  Relevant national authorities (i.e. representatives of the ministry of Health, ministry of Research, etc.);
-  Representatives of the National plan/strategy for rare diseases ;
-  European Reference Networks members;
-  Research institution involved in RD research (participating to the EJP RD or not);
-  Representatives of patient organisations;
-  Representative of Orphanet local teams.

Role of the National Mirror Groups

The main role of the NMG is to ensure that national activities, strategies and needs are taken into account when taking decisions at the EJP RD level. The Governing Board representative will report NMG views and positions during GB meetings/conference calls.

The NMGs should:

-  Coordinate the participation of national actors in the field of rare diseases 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 of rare diseases by promoting EJP RD actions and outcomes at national level.

Organisation of the work of National Mirror Groups

It is recommended that NMGs plan at least once a year face-to-face meeting. Ideally this meeting should take place in June to allow the discussion on the proposed EJP RD Annual Work Plan and provide NMG recommendations in advance of the annual Policy Board meeting that takes place in early July of each year.

If considered relevant (and to facilitate the work/discussions of specific subjects) dedicated working groups can also be established within the NMG.

Whenever needed NMG can receive support from the EJP RD coordination for the preparation/deliver of relevant documents or presentations.

