



E-RARE OBJECTIVES

E-Rare-3 will build on the experience and results of the previous E-Rare-1 & E-Rare-2 ERA-Nets, its main objectives are:

Maximizing scarce resources and coordinating research efforts are key elements for success in the area of rare diseases. The main objectives of E-Rare-3 are:

1. Funding transnational collaborative research through yearly joint transnational calls contributing to IRDiRC objectives

The co-fund call will enable pooling of resources that are available for transnational collaboration on rare disease research from national and regional programmes in 17 countries complemented by the European Commission for a total of almost 20 Mio€ to fund research on rare diseases with particular attention to implement the objectives of IRDiRC. The co-funded call will be prepared and launched according to the selection procedure and to the guidelines of the EC. The call will aim at furthering the understanding of disease mechanisms and natural history of rare diseases with the objective to develop new diagnostic tools and treatments. The information on the compliance to the IRDiRC guidelines and policies will be clearly stated in the call text and all communication documents related to the call. The objectives of IRDiRC will be further pursued by the launch of three other Joint Transnational Calls (without EC co-funding).

2. Development of the strategic research agenda

Research needs will be gathered from the Commission Expert Group on Rare Diseases and from national, European and other international organizations, networks and projects. Collaboration with FP7-funded project RARE-Bestpractices will also be established. The content of the Rare-Bestpractices research recommendation database will provide a valuable information resource for the Joint Transnational Calls. The representatives of IRDiRC Scientific Committees will be invited as members of E-Rare External Advisory Board that will be consulted at the occasion of strategic workshops.

3. Strengthen the collaboration with European Research Infrastructures

Collaboration between several EC-funded research infrastructures (EATRIS, ECRIN, BBMRI, EU-OPENSOURCE, INFRAFRONTIER) will be reinforced so that rare diseases research projects funded under E-Rare calls can benefit from their knowledge and services.

4. Involvement of patients' associations in research funding

The strength of the E-Rare consortium of public funding organizations relies on its capacity to maximize the resources for rare disease research by collaborating in Joint Transnational Calls. The need to drive research and its translation for better prevention, diagnosis and treatment is also expressed by rare disease patient organizations. In collaboration with EURORDIS E-Rare-3 will develop a model to proactively involve patient organizations in the funding of E-Rare's Joint Transnational Calls.

5. Transforming E-Rare into a sustainable network

The previous EC funding for E-Rare was instrumental to get the consortium to its current state of effectively collaborating, discussing and adjusting strategic issues and managing JTCs. The new mechanism of the ERA-Net co-fund implemented for E-Rare-3 will be the basis for consolidation and further development of the E-Rare network.

6. Ensuring that all stakeholders are actively engaged in, and informed on, the activities of E-Rare