European
Reference
Networks

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In its first workshop, the ERN Research Working Group defined what ERN research entails

After several conference calls, the members of the ERN Research Working Group met for the first time on the 24th January, to better define the scope of the "ERN research", to establish a common approach in this area, to listen to and discuss results gathered by a contractor on ERN Research capabilities and to put the basis for operational steps. Several external speakers brought relevant input to the discussion, and the agreement to set up a close collaboration with representatives of the European Joint Programme (EJP)[1] co-fund on Rare Diseases, in which all ERNs are represented, was confirmed.

The first focus of the workshop was to clarify the definition of what ERN research exactly is and thus to agree on a common definition: "any research involving an ERN" is defined as "research activity involving at least two ERN members from two different Member States for conditions or diseases covered by the ERN and specifically naming the ERN". A second objective was to provide an overview of current ERN research capabilities and the current research landscape for ERNs, this was done by Jonathan Olsson Consulting which had been contracted by the Commission to conduct a survey and support the Working Group.

Representatives of the European Joint Programme (EJP) co-fund on Rare Diseases were also invited and agreed with the Working group a general consensus to closely work together, while the representative of the RD-Action project summarised the conclusions of the workshop held in May 2018[2] in London on how ERNs can provided added value in the area of clinical research.

Finally, in the afternoon, a discussion took place to define the role of the Working Group, its main aim being to facilitate research efforts deployed by the ERNs, to guide them and provide support, while not performing research directly but promoting joint efforts. Common needs have been identified, among them strengthening the sharing of information on research calls and projects, promoting advocacy and adopting a multidisciplinary approach to research.

Early 2019, almost all ERNs have a dedicated group and/or transversal work package(s) specifically dedicated to research. The ERN Research Working group is composed of members of all 24 ERNs and of representatives of the ERN Board of Member States. The Working Group will continue supporting the ERNs in their research activities, in particular in areas of common interest such as registries,

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[1] http://www.ejprarediseases.org/
[2] http://www.rd-action.eu/

clinical trials and relations with the European Medicines Agency (EMA), and synergies with the EJP or projects such as Solve-RD[3] (Solving the Unsolved Rare Diseases) will be further enhanced.

ERNs are already involved in research in the framework of the European Joint Programme on Rare Diseases (EJP) which brings over 130 institutions from 35 countries to create a comprehensive, sustainable ecosystem allowing a virtuous circle between research, care and medical innovation in the field of rare diseases. Launched in January 2019 the initiative establishes closed bridges with the ERNs to enable synergies and economy of scale[4].

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[3] http://solve-rd.eu/

[4] http://www.ejprarediseases.org