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Support for the setting-up of registries of patients affected by rare diseases available for all the ERNs

On the 14th May, a new Call for proposals was published by the European Commission¹ to allow 19 out of the 24 current European Reference Networks (ERNs) to submit proposals and receive financial support for the setting-up of registries in their respective fields of expertise. Five ERNs already receive grants for this purpose. This publication of this call happened on the same day the networks discussed their work on the registries in the framework of their cross-ERN Research Working Group.

The registries are fundamental tools for research purposes and are particularly important to establish in the field of rare diseases where the data are fragmented: they become even more relevant to follow cohorts of patients and thus the natural course of diseases, as well as to possibly find diagnosis and treatments. Thanks to the ERNs, the critical mass of available data makes the exercise more meaningful. Five ERNs already receive a financial support: their projects started at the beginning of 2018 for a duration of three years. While their work is still in progress, the newly published call will enable the 19 other ERNs to do the same, by submitting proposals before the 10th September 2019. The 19 ERNs are invited to enhance synergies between them (and the five other ERNs, also learning from them). Candidates can apply for a grant to develop their own approach in terms of registries, and decide whether to apply individually or to work together through a joint applications.

Also on 14th May, the Research Working Group of the ERNs² had an extensive discussion on the registries, where the current five ERNs which are already developing their registries could illustrate the work conducted so far. ERKNet³, Endo-ERN⁴, MetabERN⁵, ERN-LUNG⁶ and ERN PaedCan⁷ explained their own projects. Most of these registries have been built upon existing collaborations while filling in gaps and constructing comprehensive approaches for their respective Networks. The other participants from the networks could learn from their experience and the discussion was very useful both at individual level and for the whole ERN community of researchers. The members of the Working group also introduced also their short survey conducted among the members to map the needs of the ERNs in terms of registries.

¹ http://ec.europa.eu/chafea/health/newsroom/news/14052019-01/index_en.htm

² The Research Working Group is composed of ERNs coordinators and Research leads as well as of representatives of the ERN Board of Member States (BoMS).

³ https://www.erknet.org/index.php?id=reg_about

⁴ <https://eurreca.net/>

⁵ <https://u-imd.org/>

⁶ <https://ern-lung.eu/ern-lung-rd-registry-data-warehouse/>

⁷ <https://www.raretumors-children.eu/about-us/partner-project/>



The Commission is supporting also the action of the ERNs in the field of registries through the collaboration between two Directorate-general of the Commission, namely DG SANTE and the Joint Research Centre (JRC), which developed tools that will help the European rare disease community in general and the ERNs in particular: the European Platform on Rare Disease Registration⁸, JRC Set of Common Data Elements for Rare Disease Registration and a Pseudonymisation tool put at the disposal of registries joining the Platform.

⁸ <https://eu-rd-platform.jrc.ec.europa.eu/>