

## CALL FOR PROPOSALS PP-2-1-2016

### Call for proposals on Establishing a registry of rare congenital malformations (as part of the Rare Disease Registry), drawing on the structure, organisation and experience of the Registry of Congenital Malformations

**Rare diseases (RD)** are diseases with a particularly low prevalence. In the European Union diseases are considered to be rare when they affect no more than 5 per 10 000 persons. Based on present scientific knowledge, there are between 6 000 and 8 000 distinct RD (currently 5 860 are described in the Orphanet database – European portal of RD and orphan drugs) that affect between 6% and 8% of the EU population in the course of their lives. In other words, between 27 and 36 million people in the European Union are affected by a rare disease.

The Financing Decision for the pilot project "Establishing a registry of rare congenital malformations (as part of the Rare Disease Registry), drawing on the structure, organisation and experience of the Registry of Congenital Malformations" was adopted on 08 September 2016. Its Annex sets out the main priority areas for this pilot project on registry of rare congenital malformations to be implemented through the present call :

- The key objective of this pilot project is to set up a registry of rare congenital malformations as a part of rare diseases national registers. The project should be implemented at a national level.
- The secondary aim of the project is to provide an example of how to extend an existing birth defects registration and surveillance system to a rare diseases registration system.
- The birth defects registration system has already been set up in several MSs as part of the EUROCAT surveillance network. The pilot project provides a model for exploring whether a birth defects registry can be extended to form a rare diseases registry.
- The pilot project should contribute to the development of an EU Platform on Rare Diseases Registration to provide a common access point to data collections on rare diseases across Europe and to be compatible with platform tools.

The activities funded will be implemented within a period of no longer than 24 months.

Link to the participant portal with relevant info:

<https://ec.europa.eu/research/participants/portal/desktop/en/opportunities/index.html>

#### Contacts

For problems with the online submission tools please contact the IT helpdesk set-up for this purpose via the participant portal website: <http://ec.europa.eu/research/index.cfm?pg=enquiries>

For non-IT related questions, please contact DG SANTE helpdesk at the European Commission email: [SANTE-PP-CALLS@ec.europa.eu](mailto:SANTE-PP-CALLS@ec.europa.eu)

In all correspondence relating to this call (e.g. when requesting information, or submitting an application), reference must be clearly made to this specific call. Once the electronic exchange system allocated a proposal ID, the applicant must use this number in all subsequent correspondence.