

CALL FOR PROPOSALS PP-1-2-2018

Call for proposals on Rare 2030 - a participatory foresight study for policy-making rare diseases

In the European Union, a disease is considered rare when it affects not more than 1 person in 2.000. This low prevalence is the common feature shared by all rare diseases, which altogether affect all biological systems. This nevertheless means that between 6 000 and 8 000 different rare diseases affect or will affect an estimated 30 million people in the European Union.

The Financing Decision for the pilot project "Rare 2030 - a participatory foresight study for policy-making rare diseases" was adopted on 15 December 2017. Its Annex sets out the main Work packages for this pilot project on Rare 2030 - a participatory foresight study for policy-making rare diseases:

- base research, including literature reviews and exploratory interviews to identify drivers of change and current and future challenges; - establishment of an expert / multi-stakeholder panel;
- consensus building methods will be used to define the main drivers (political, scientific, etc.) for scenario building and will be open to large groups of stakeholders on a European level;
- an interdisciplinary and forward-looking workshop for scenario building will be used as a tool to reveal available choices and their potential consequences; the scenarios developed will take into account resources at EU level, and include options to use the existing structures better, in particular the framework of the European Reference Networks (ERN) and the Steering Group on Promotion and Prevention (SGPP).
- EU added value will be defined in options for action at EU level, both as theoretical concept and in terms of practical scenarios, with a clear distinction from actions recommended at national level.
- extended patient consultation (survey) on the identified scenarios;
- a European 'consensus conference' ('conférence de citoyens') to present, discuss and review results, engaging society to shape and take ownership of the outcomes;
- identification of sustainable options for future action, bringing together the results of the scenarios and conference;
- a final report, in English, outlining the options for future action and outcomes of the project and measuring its impact; the executive summary of the report will be translated into various EU languages;

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>. The call can be found under the title [Pilot Project](#).

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

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

