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ANNEX 1

ANNEX

to the

COMMISSION DECISION

on the adoption of a financing decision for 2017 and 2018 for the pilot project "Pilot project - Rare 2030 - a participatory foresight study for policy-making rare diseases"

ANNEX

Pilot project – " Pilot project - Rare 2030 - a participatory foresight study for policy-making rare diseases – Work programme for 2017 and 2018"

1.1. Introduction

On the basis of the objectives given in the budget remarks this work programme contains the actions to be financed and the budget breakdown for year 2017 and 2018 as follows:

for grant (implemented under direct management) (1.2): EUR 1 300 000

1.2. Grants

Pilot project - Rare 2030 - a participatory foresight study for policy-making rare diseases – Work programme for 2017 and 2018

1.3. LEGAL BASIS

Pilot project within the meaning of Article 54(2) of Regulation (EU, Euratom) No 966/2012 of the European Parliament and of the Council of 25 October 2012 on the financial rules applicable to the general budget of the Union and repealing Council Regulation (EC, Euratom) No 1605/2002 (OJ L 298, 26.10.2012, p. 1).

Budget line

17 03 77 28

Priorities of the year, objectives pursued and expected results

Rare 2030 is a two-year project, led by a research team, but using inclusive methods to promote a focus on EU added value.

A continuous bottom-up approach will be used so as to put more emphasis on interaction and to encourage a broad take-up by patients, stakeholders and society at large of approaches developed at EU level.

The purpose of the pilot project is to propose sustainable policy scenarios in the field of rare diseases for the period 2020-2030 and to address challenges and opportunities up until 2030 in an innovative manner, with particular emphasis on limited competences at EU level, and use of existing structures, in particular European Reference Networks (ERNs) and the Steering Group on Promotion and Prevention (SGPP)

Description of the activities to be funded under the call for proposals

The methodological steps and timeline for Rare 2030 will include different work packages:

- 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). No new structure at EU level should be proposed;
- 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 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.

All project activities will be implemented in close collaboration with relevant Commission services, and relevant EU-funded activities in the area of rare diseases (e.g. Joint Action on Rare Diseases).

Essential eligibility, selection¹ and award criteria²

ADMISSIBILITY, EXCLUSION AND ELIGIBILITY CRITERIA.

Admissibility criteria

Proposals received after the deadline for submission laid down in the call for proposals will not be considered for funding. Other formal requirements regarding the grant application will be specified in the call for proposals.

Exclusion criteria

Applicants will be excluded from participation in an award procedure if they are in any of the situations of exclusion listed in Articles 106 and 107 of the Financial Regulation.

Eligibility criteria

Proposals must be submitted by consortia of legal entities (with or without legal personality) established in at least 2 different EU Member States. Actions that have already commenced by the date on which the grant application is registered will be excluded from participation.

¹ In accordance with Article 131 of Regulation (EU, Euratom) No 966/2012 the verification of financial capacity shall not apply to natural persons in receipt of scholarships, to natural persons most in need and in receipt of direct support, to public bodies or to international organisations. The authorising officer may, depending on a risk assessment waive the obligation to verify the operational capacity of public bodies or international organisations.

² In case of grants awarded without a call for proposals on the basis of Article 190 of Delegated Regulation (EU) No 1268/2012 or under a framework partnership the essential eligibility criteria are not to be specified since the description of the action shall specify the bodies to which grants may be awarded. Nevertheless the selection and award criteria shall be mentioned in all cases including for specific grants, even if those criteria are already provided in the framework partnership agreement or decision.

SELECTION CRITERIA

Only proposals which meet the exclusion and eligibility criteria will be assessed on the basis of the selection criteria. The following selection criteria have to be met.

1. Financial capacity

Applicants must have stable and sufficient sources of funding to maintain their activity throughout the period during which the activity is being carried out and to participate in its co-financing.

The verification of financial capacity will not apply to public bodies and international public organisations.

2. Operational capacity

Applicants must have the professional resources, competences and qualifications required to complete the proposed action.

AWARD CRITERIA

Only projects which meet the exclusion and eligibility and selection criteria will be further evaluated on the basis of the following award criteria.

1. Policy and contextual relevance (40 points, threshold: 20 points):

(a) Project's contribution to meeting the objectives and priorities defined in the financing decision (8 points);

(b) Strategic relevance with regard to the EU Health Strategy (COM (2007) 630 final; http://ec.europa.eu/health/ph_overview/strategy/health_strategy_en.htm) and with regard to expected contribution to existing knowledge and implications for health (8 points);

(c) Added value at EU level in the field of public health (8 points):

- impact on target groups, long-term effect and potential multiplier effect, such as replicable, transferable and sustainable activities,
- contribution to complementarity, synergy and compatibility with relevant EU policies and programmes;

(d) Pertinence of geographical coverage (8 points):

Applicants must ensure that the geographical coverage of the project is commensurate with its objectives, and explain the role of eligible countries as partners and the relevance of project resources or the target populations they represent;

(e) Social, cultural and political context (8 points):

Applicants must explain how the project relates to the situation of the countries or specific areas involved, ensuring the compatibility of envisaged actions with the culture and views of the target groups.

2. Technical quality (30 points, threshold: 15 points):

(a) Evidence base (6 points):

Applicants must include a problem analysis and clearly describe the factors, impact, effectiveness and applicability of the proposed measures;

- (b) Content specification (6 points):
Applicants must clearly describe aims and objectives, target groups, including relevant geographical factors, methods, anticipated effects and outcomes;
- (c) Innovative nature, technical complementarity and avoidance of duplication of other existing actions at EU level (6 points):
Applicants must clearly identify the progress that is expected to result from the project within a given field in relation to the state of the art and ensure that there will be neither inappropriate duplication nor overlap, whether partial or total, between projects and activities already carried out at EU and international level;
- (d) Evaluation strategy (6 points):
Applicants must clearly explain the methods proposed and indicators chosen and their adequacy;
- (e) Dissemination strategy (6 points):
Applicants must clearly illustrate the adequacy of the envisaged strategy and methodology to ensure transferability of results and sustainability of dissemination.
3. Management quality and budget (30 points, threshold: 15 points):
- (a) Planning and organisation (5 points):
Applicants must clearly describe the activities to be undertaken, timetable and milestones, deliverables, nature and distribution of tasks, and provide a risk analysis;
- (b) Organisational capacity (5 points):
Applicants must clearly demonstrate the quality level of the structure of the project by describing its management structure, competence of staff, responsibilities, internal communication, decision-making, monitoring and supervision;
- (c) Quality of partnership (5 points):
Applicants must clearly describe the partnerships envisaged in terms of extensiveness, roles and responsibilities, relationships between the partners, and the synergy and complementarity of partners and network structure;
- (d) Communication strategy (5 points):
Applicants must clearly describe the communication strategy in terms of planning, target groups, adequacy of channels used, and visibility of EU co-financing;
- (e) Overall and detailed budget, including financial management (10 points, threshold: 5 points):
Applicants must ensure that the budget is relevant, appropriate, balanced and consistent in itself, between partners and in relation to the specific objectives of the project. The budget should be distributed between partners at a minimum reasonable level, avoiding excessive fragmentation.
Applicants must clearly describe financial circuits, responsibilities, reporting

procedures and controls.

Any proposal which does not reach all the thresholds will be rejected.

Following the evaluation, a list is drawn up containing proposals reaching all the thresholds and ranked according to the total number of points awarded. Only the highest ranked proposal will be awarded co-financing.

Implementation

Through a call for proposals managed by DG SANTE. Only 1 grant will be awarded.

Indicative timetable and indicative amount of the call for proposals

Reference	Date	Amount
Launch of the call for proposals	First semester 2018	1 300 000 EUR

Maximum possible rate of co-financing of the eligible total costs

The maximum rate for EU co-financing is 60 %