European Reference Networks

The sustainability challenge

4th ERN Conference

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2017-2022

Health Programme Financial support and results

Activities of ERNs co-funded under the health programme

**Financing decision
(Annual Work programme 2016):**

"Coordination, management and non-clinical activities of an approved ERN in support of ERN goals "

Coordinators can request support for

(i) networking and coordination activities;

(ii) administrative and logistic support

(iii) development of knowledge generation tools (clinical guidelines, patient pathways);

(iv) training and eLearning activities; and

(v) meetings of the network members and participation in conferences or events related to the network's area of expertise;

Providing a better governance and coordination so that ERNs can:

(i) offer the possibility to work in multidisciplinary teams across different EU countries;

(ii) increase the level of expertise;

(iii) build capacity to produce good practice guidelines, to implement outcome measures and quality control;

(iv) provide support to research coordination and teaching and training activities;

Main funding scheme 24 ERNs

Mono-beneficiary grants:
Awarded to the ERN Coordinator

Duration:
23 ERNs: 1/03/2017-28/02/2022
5-years Framework Partnership Agreement (FPA);
3 Specific Grant Agreements (SGAs) covering:
1st year , 2nd year; 3-5th year

1 ERN: 3 year 1/06/2018-31/5/2021

Funding amount:
Up to EUR 200 000 per network and per year
Total EUR 23 600 000

Other funding

Project grants for registries:
Call in 2016
5 projects funded for EUR 1 979 361

Procurement
Clinical decision support tools: taxonomy and templates for deliverables, including training EUR 400 000
Development of clinical guidelines EUR 4 million
Networking, communication and coordination between networks (several service contracts)

Achievements 18 months on

Internal Coordination:
All ERNs have established their **governance models** and **Quality Assurance Plans** or other **Standard Operating Procedures (SOPs)** for their working procedures

Dissemination:
All ERNs have established specific **dissemination and communication plans** and **websites**

Evaluation:
All ERNs have established internal **evaluation activities**

Achievements 18 months on

Clinical management tools
All ERNs have established or further developed their own **databases and/or registries**

Clinical Guidelines
Most ERNs have developed **clinical guidelines** in their field of activity

Clinical Patient Management System (CPMS*)
All ERNs are using or are preparing to use the IT Platform for clinical consultations between ERN Members

* funded through the Connecting Europe Facility (CEF)

European Commission

Consumers, Health,
Agriculture and Food
Executive Agency

Achievements 18 months on

Scientific and clinical cooperation
Setup of working groups bringing together leading European centres:

Education, Clinical Guidelines and recommendations, **Registries and Bio banks**, IT and e-Health, **Molecular Testing**, Patient Organisations and on Communication
Stem Cell and Gene Therapy, Transition Care, **Pharmaco-vigilance and Biological Therapies**

Post 2022

Translating financial and technical support into sustainable operations

European Commission

Consumers, Health, Agriculture and Food Executive Agency

Optimize the initial funding rounds to achieve sustainable operations

Technical sustainability
Moving from best practice sharing and show-casing to **standardization** (sharing of experience and capacity building)

Moving from ad-hoc assessment (currently undertaken by the Independent Assessment Bodies) to an **internal system of quality improvement**

Optimize the initial funding round to achieve sustainable operations

Financial sustainability

Additional funding for the implementation and following phases is to be included under the new MFF;

Support sustainability also requires:

- ➢ The whole network takes ownership & activities are integrated into HCP general operational framework and into national health systems
- ➢ Using the health programme to access other (multiple, bigger and more appropriate funding sources)