

Joint brainstorming session

ERN Board of Member States

&

ERN Coordinators Group

18 September 2020

Housekeeping rules

- Please keep your microphones muted, only 'unmute' when you speak.
- Please switch off your video, we will work with audio only.
- Please use the chat box for any questions, remarks, or if you would like to speak. The chat will be copied for the purpose of minute taking.
- This meeting will be recorded for the purpose of minute taking (if you do not wish to be recorded you can choose to listen and not intervene vocally or you can choose to leave the meeting).
- Many thanks for your cooperation.

Agenda

1.	9:00 – 9:10	Welcome and opening
2.	9:10 – 9:25	EU4Health state of play Presentation: Commission <i>Information point</i>
3.	9.25 – 10:30	Financing of ERNs - Identification of priority areas to be supported (in view of the reduced EU4Health Programme) <ul style="list-style-type: none"> ○ Which are the main priorities and needs for ERN funding, taking into account the limits of the EU budget? ○ How to best use national funding or other instruments (e.g. Resilience and Recovery Facility, RRF) to support ERNs in addition to the support provided from EU4Health Programme? ○ How best demonstrate value for money of the ERNs? How to best establish specific objectives and define indicators linked to the provision of funding in order to demonstrate the benefits of the ERN system for patients and healthcare systems? <i>Brainstorming</i>
	10:30 – 10:40	Coffee break
4.	10:40 – 11:50	Governance and integration of ERNs into national systems - What are the main challenges? - How to pursue integration into the national healthcare systems? <ul style="list-style-type: none"> ○ National (sub-)networks. ○ Joint Action (JA) on Integration of ERNs. → Are Member States and Coordinators willing to participate in it? → Brainstorming regarding the scope of the JA and its complementarity to the ongoing actions. → Brainstorming on main areas of action, potential work packages and potential deliverables. <i>Brainstorming</i>
5.	11:50 – 12.00	Any other business

EU4Health programme

- Information point on the state of play



European
Reference
Networks



European
Commission

EU4Health programme

- Commission proposal adopted on 28 May 2020
- In July, the European Council reached an agreement on the budget underlying the COVID-19 recovery and the Multiannual Financial Framework.
- That deal, however, represents a substantial cut for the EU4Health Programme.
- The original proposal of €9.4 billion has been reduced to €1.7 billion over the period 2021-2027.
- Negotiations with the Parliament and the Council are ongoing.

GOAL

Survival/improved health of patients affected by rare diseases (RD)

ERNs' OBJECTIVE

Equal access of patients affected by rare diseases to diagnosis and treatment, regardless of their origin and disease

PILLAR 1 ACCESSIBILITY

ACHIEVEMENT 1: Patients know where to go to find support for their health

OBJECTIVE 1
Structure a clear access to services at EU/national/local level

ACTIONS:
Define national referral systems /clear pathways, direct access to the members of the ERNs/access to the national networks/access to the CPMS

PILLAR 2 KNOWLEDGE GENERATION & PROFESSIONAL CAPACITY BUILDING

ACHIEVEMENT 2: Healthcare professionals have access to the right knowledge and expertise to diagnose, manage or treat patients.

OBJECTIVE 2
Provide clinicians with expertise and clinical tools

ACTIONS:
Clinical practice guidelines
Clinical Decision Support Tool
Access to the right knowledge and expertise to diagnose
E-training and e-learning

PILLAR 3 RESEARCH

ACHIEVEMENT 3: new diagnosis and treatments are available for all rare diseases

OBJECTIVE 3
Improve the knowledge on the epidemiology and genetic base of the RD

ACTIONS:
Research projects
Registries/health data management
Clinical trials
AI developments and tools
Publications in the scientific journals

PILLAR 4 HEALTHCARE SYSTEMS EFFICIENCY

ACHIEVEMENT 4: efficient healthcare systems are in place to care for rare diseases patients

OBJECTIVE 4
Contribute to the efficiency and resilience of healthcare systems to support and care RD patients

ACTIONS:
Integration strategies
National Networks
National referral systems
Clear patients pathways for RD
Accessibility to the national networks

TRANSVERSAL PILLAR

ERN data strategy

ERNs system governance and structure

Financing of ERNs

Brainstorming



European
Reference
Networks



European
Commission

Questions

- Which are the main priorities and needs for ERN funding, taking into account the limits of the EU budget?
- How to best use national funding or other instruments (e.g. Resilience and Recovery Facility, RRF) to support ERNs in addition to the support provided from EU4Health Programme?
- How best demonstrate value for money of the ERNs? How to best establish specific objectives and define indicators linked to the provision of funding in order to demonstrate the benefits of the ERN system for patients and healthcare systems?

Governance and integration of ERNs into the national health systems

Brainstorming

Questions

- **What are the main challenges?**
- **How to pursue integration into the national healthcare systems?**
 - National (sub-)networks.
 - Joint Action (JA) on Integration of ERNs.
 - Are Member States and Coordinators willing to participate in it?
 - Brainstorming regarding the scope of the JA and its complementarity to the ongoing actions.
 - Brainstorming on main areas of action, potential work packages and potential deliverables.

On the Joint Action

- Under the leadership of Member States
- Grants for co-financed actions, awarded without calls for proposals
- Member States' authorities invited to nominate one competent authority responsible for implementing the action on their behalf. In addition, “affiliated entities” also eligible to participate.
- The competent authorities to identify and select the civil society organisations active at EU level as collaborating partners and/or to participate in advisory structures.

On the Joint Action

Example of timeline (in 2020):

- Invitation to MS to nominate competent authorities (CAs): March 2020, deadline May 2020
- Invitation to nominated CAs to submit proposals: June 2020, deadline October 2020
- Evaluation, Grant agreement signature, Start of the Joint Action: Q1 2021
- Duration of the Joint Action: usually 2-3 years.

What is needed for successful Joint Action?

- To identify interested Member States whose CAs will actively contribute
- To identify the right working areas (work packages)
- To identify the right expected results/deliverables of the action

Potential areas of action

- Starting point: 2019 Statement of the ERN BoMS on Integration of the ERNs to MS healthcare systems
- Potential areas:
 - Governance framework for ERNs integration to the national systems
 - Patient care pathways
 - Referral systems to the ERNs
 - Awareness raising on ERNs at national level
 - Sustainability of the ERN model at HCP level

Keep in touch



ERN overview:

https://ec.europa.eu/health/ern_en



ERNs and Covid19:

https://ec.europa.eu/health/ern/covid-19_en



ERN videos:

https://ec.europa.eu/health/ern/videos_en



@EU_Health

Thank you



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