ERNs at five years from their launch; situation and future

26th April 2022

Jose A. Valverde
DG SANTE - European Commission
jose.VALVERDE-ALBACETE@ec.europa.eu
European Reference Networks

https://ec.europa.eu/health/ern_en
Key achievements so far

Established structure
- Clear Legal Basis and Institutional framework
- Consolidated governance structure and networking capacity
- EU funding sources available
- Joint ownership (Member States authorities, patients, health professionals, hospitals, EU institutions)
- Strong political support (EU) and perceived as a good example of European cooperation
- 24 Networks started their clinical work with patients

Actions and outcomes
- Clinical cooperation, patient cases discussed virtually (CPMS)
- Knowledge Generation and development of training, education and awareness actions
- Development and implementation of clinical practice guidelines
- Important number of scientific publications
- Development of research projects
- Support for ERN patient registries as part of EHDS

2017
- Setting up

2019
- Affiliated partners

2022
- Enlargement
Content

- Enlargement
- Funding
- Evaluation & monitoring
- Future actions
Enlargement of the Networks (01/01/2022)

- 843 Applications
- 630 Assessed by IAB
- 620 New members
- 846 Old members

~ 1600 HCP Units

All MS + Norway covered

Full members + Affiliated partners
Content

Enlargement

Evaluation & monitoring

Funding

Future actions
Funding

• Adopted 27 March 2021
• EU4Health Programme 2021-2027
• €5.3 billion for actions with an EU added value
• ERNs in programme’s specific objectives
Funding – Bridge Direct Grant

CEF
Registries
Coordination

2022

“Bridge”
Direct Grant

2023

New “Consolidated” Direct Grants

2027

• Same type as current ERNs Coordination grants; same financial & administrative reporting rules;
• Up to 100% eligible costs;
• Start 1st March 2022;
• Overall budget: 26 mill. EUR for all 24 ERNs
• Duration 18 months;
• NO competitive call, but through the Funding & Tender Opportunities portal;

* Avoid double-funding between “Bridge direct grant” and CEF/Registries
Content

- Enlargement
- Funding
- Evaluation & monitoring
- Future actions
**AMEQUIS**

- **Assessment**
- **Monitoring**
- **Evaluation**
- **Quality**
- **Improvement**
- **System**

*Initial assessment* of networks (Delegated Decision 2014/286/EU)

*Continuous monitoring* of performance of ERNs and their members (18 common indicators (structure, process and outcomes) agreed by ERNs)

*Periodic evaluation* of performance of the networks and their members, **five years** after their approval or last evaluation (Implementing Decision 2014/287/EU)
5 years evaluation

• Methodology, manual and procedure for the evaluation; to be completed in Q1 2022. Final AMEQUIS conference organised on 18/01/2022

• Appointment of new Independent Assessment and Evaluation body: 1st half 2022

• Start of the ERN 5-year evaluation: 2nd half 2022

• Final evaluation reports on each network and each member: 2023
Content

Enlargement

Funding

Evaluation & monitoring

Future actions
Future actions

**New IT tools**
- New CPMS
- EU Academy

**Continuous training**
- ERN Clinical Practice Guidelines programme
- ERN Professional mobility programme

**Research & registries**
- ERICA & EJP-RD
- European Health Data Space

**Integration**
- Joint Action on ERN integration into national healthcare systems (2022)
Thank you for your attention

Further information: