

ERNs at five years from their launch; situation and future

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European Reference Networks



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





Key achievements so far

24 ERNs



2017

Setting up

2019

Affiliated partners

2022

Enlargement

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



Enlargement Funding Evaluation Future actions & monitoring



Enlargement of the Networks (01/01/2022)

843 Applications

630 Assessed by IAB

All MS + Norway covered

846

620

New members

Old members

1466 + 288*

Full members

Affiliated partners











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

"Bridge"
Direct Grant
2022 = 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

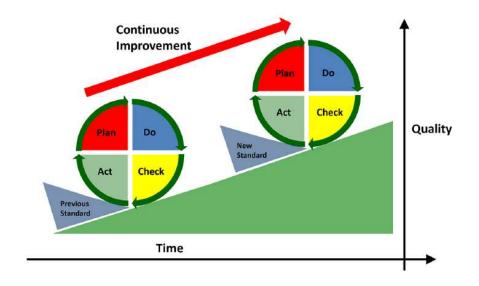






AMEQUIS

- 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









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)













Further information: http://ec.europa.eu/health/ern/policy/index en.htm





