




**EVALUATION OF THE ERN SYSTEM**  
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Co-funded by the EU

### ERN SYSTEM

- Participants of the ERN system:
  - ERNs
  - ERN units
  - ERN coordinator
  - ERN CG
  - Hospitals
  - Member states
  - Board of MS
  - ePAGs
  - ePAG SG
  - Patient organisations
  - EURORDIS
  - DG SANTE
  - HADEA
- (Funded) core of the ERN activities
  - Cross-border cooperation of ERN units
  - Coordination
  - CPMS
  - Training
  - Guidelines and Care Standards
  - Registry

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### EVALUATION OF ERN SYSTEM

- Evaluation participants:
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  - EURORDIS
  - DG SANTE
  - HADEA
  - Etc.
- Focus of Evaluation
  - ERN system
- Conclusions 1
  - ERNs, ERN units, ERN coordinators are only accountable for a part of the ERN system
  - However, ERNs, ERN units, ERN coordinators were evaluated **as if** they are the entire ERN system
- Conclusion 2
  - Evaluation of ERNs – funded European level of ERNs - led to very good results – indicator for maturity of ERNs
  - Evaluation of ERN units – unfunded local and national level of ERNs (including hospitals, member states) – led to a lot of frustration

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### OUTCOMES

- All **24 Networks** obtained 'satisfactory' results. The networks are therefore maintained;
- 733 Healthcare Providers** (88% of assessed HCPs) obtained 'satisfactory' results. These HCPs are therefore maintained members of the ERNs;
- 71 Healthcare Providers** (8% of assessed HCPs) obtained 'needs improvement' and submitted an improvement plan. These will be re-evaluated in one year after the implementation of the plan, which they submitted to the Independent Evaluation Body.
- 25 Healthcare Providers** (3% of assessed HCPs) obtained either 'needs improvement' but did not submit an improvement plan (9 HCPs) or did not complete the self-assessment (16 HCPs). The membership of these HCPs was terminated;
- 1 Healthcare Provider** obtained needs improvement result and did not submit an improvement plan. An extension to submit the improvement plan by 13 November 2023 was decided by the Board of Member States.

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### EVALUATION – GENERAL REMARKS FROM ERN PERSPECTIVE

- ERN evaluation was necessary based on legal framework
  - ERN passed this test – important milestone for ERN system !!!
- Technical goals of evaluation
  - To measure against criteria
  - To understand – identification and analysis of mechanisms by which outcomes are produced
  - To learn – how the program can be improved

Works as long as the framing of the evaluation and the evaluated program are a good match.
- Improvement of evaluation
  - Results from survey of all ERN coordination offices (see next slides)

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### WHAT WERE THE 3 MAIN ISSUES FACED BY ERN HCPs REGARDING EVALUATION?

- Main focus on hospital not expertise centre
- No coordination with national activities
- No support from HCP managements/administrations
- Language - translation of documents and interviews into English
- Formulation of measurable elements
- Time needed for the evaluation
- Relevance of the evaluation

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## WHAT THINGS WENT WELL WITH THE ERN EVALUATION AS REPORTED BY ERN HCPs?

- 1) Responsivity of IEB
- 2) Friendliness of auditors



## HOW CAN THE ERN EVALUATION BE IMPROVED?

- 1) Revision of the ERN Evaluation to focus on the specific expertise required to be a member of a specific Network and on the actual participation of the HCPs in the activities of the Network
- 2) Take into consideration national systems and avoid overlap; leave evaluation of HCPs to member states altogether
- 3) Focus evaluation on structures and processes that ERN units can change/improve
- 4) Ensure homogeneity of evaluation across evaluators - same information led to different scores/evaluation
- 5) Align with ERN monitoring - build integrated system
- 6) Involve ERNs in improvement of evaluation - form a respective ERN CG, BoMS, DG SANTE working group



## EVALUATION – TIME SPENT

### By ERN coordination offices

- On average 275 hours = about 2 person months

### By HCPs that got an onsite audit

- 193 audits
  - per audit 6 person days for preparation and actual audit = 1,158 person days of **THE EUROPEAN RD EXPERTS**
- 7 patients per day → > 8,100 patients  
→ €60 per hour → >€500,000

### By all evaluated ERN HCPs ...



## ERN EVALUATION – HOW CAN THE SYSTEM BE IMPROVED?

### We need a systematic evaluation of the evaluation

### Mean

HADEA / BoMS / ERN / JARDIN Working Group on improvement of evaluation



THANK YOU

