



The European Reference Networks An overview

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Objective of this presentation:

- update on the establishment of the ERNs
- procedure for new HCPs joining existing ERNs
- role of NCPs in relation to ERNs



- voluntary cooperation in healthcare established by Directive 2011/24/EU on the application of patients' rights in cross-border healthcare
- focus on rare, low prevalence and complex diseases
 - 6 7 000 rare diseases
 - 30 000 000 patients (6 8 %)
- 2 main objectives of ERNs
 - facilitate diagnoses and treatment
 - promote research



24 ERNs – Vilnius (9 March 2017)

- BOND bone disorders
- ERKNet kidney diseases
- EuroBloodNet haematological diseases
- RND neurological diseases
- Skin
- EYE
- GUARD HEART



- more than 900 units
- from more than 300 hospitals
- in 26 countries:
 25 Member States (- MT SK EL)
 + Norway
- the role of the Member States



The ERNs: how do they work?

- the patient is addressed to the ERN by a health care provider the "referral system" is in the process of being developed in each Member State national competence!
- no "auto-referral" by a patient
- free of charge advise



The ERNs: how do they work?

- virtual consultation panel
- advise on diagnoses / treatment
- patients are not travelling, knowledge is!
- a smart, efficient and cost-saving system of pooling knowledge and expertise from excellency centres across Europe and make it available where needed



The ERNs: Mobility?

- the exception, not the rule
- current legal framework
- rather limited number of patients
- based on the advice of excellency centres!



Invitation process for new HCPs to join existing ERNs

Our objective:

- ensure an objective, transparent and effective enlargement process
 - matching the development needs of each ERN in terms of special expertise as well as diseases and geographical coverage
 - bringing into the ERNs clinical and technological excellence
- thorough assessment process / clear and transparent selection criteria.



Invitation process for new HCPs to join existing ERNs

Preliminary steps:

invite the Coordinators to

- update, if necessary the network-specific selection criteria that were prepared by each of them in 2016
- prepare a Mapping document assessing the geographical and scientific/diseases gaps for each network and defining the network development needs (types/number/geographic origin of wished for members)



The envisaged procedure



Request for favourable pre-assessment

Signed favourable pre-assessment



If no favourable pre-ass. the procedure ends

ERN

Applicant HCP



Request for Endorsement

Signed Endorsement



If no endors. the procedure ends



National health Ministry



Applicant HCP

Signed application, Self-Assessment and all supporting docs





Assessment of the applications



Eligibility check





Technical assessment



Independent Assessment Body



ERN members' approval





Invitation process for new HCPs to join existing ERNs

Amendments

to the Commission Implementing Decision 2014/287/EU of 10 March 2014

First debate in the meeting of the ERN BoMS (10/10/2017)

Your view?



Role of NCPs in relation to ERNs

- ERNs were presented to the NCPs in their last meeting
- great interest raised
- questioning about the role that NCPs could play
- ad-hoc group (DE, EE, IE, UK)



