

ERNS' MAIN CHALLENGES FOR THE FUTURE

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DISCLOSURES

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- No Industry relationships

FUTURE?

- I will divide the future into "near future" and "far away future" which is beyond the first 5 years.

CHALLENGES FOR ERNS IN THE NEAR FUTURE

- Work should properly start:
 - Can the ERN's demonstrate figures about consultations, meetings, developed recommendations etc?
- ERN's may have to decide how to focus their work:
 - Is it possible to cover the whole field or prioritize to some diseases?
 - Would it be more realistic to, for instance, concentrate to consultations and leave creating registries to a later stage?
- ERN's should aim at covering all EU (and beyond):
 - All MSs need to have the possibility to participate in the way that best suits their size, expertise, training needs etc.
- How knowledge from ERNs can reach the whole national health care systems
 - MSs have to develop good national networks.

CHALLENGES FOR ERNS BEYOND 5 YEARS

- A main challenge will be resources!
 - ERN's may get grants from EU and private funding from elsewhere, but the main resource of the ERNs are the Centres of Expertise (CEs) in the Member States.
 - Hospitals in the MSs are willing to fund the active participation CEs in the ERNs if the ERNs are able to provide evidence that patients as well as the health care system really benefit from ERNs.
 - CEs may be overloaded with work: Are there enough highly specialized experts for the work? Could ERNs facilitate training of new experts?

CHALLENGES FOR ERNS BEYOND 5 YEARS

- Another big challenge will be trust!
 - Can ERNs reliably demonstrate that their work is of high quality?
 - Could the ERNs convince all stakeholders that there is an ideal balance between improving diagnostics, treatment and care and developing the field for the future by creating infrastructures/research etc.
 - Clinical trials tailored for RD are needed. The funding from Pharma Industry coming to CEs for these trials has to be fully transparent.
 - Is it possible to establish a clear framework for ERN level collaboration with Pharma Industry, including receiving funding, without compromising ERNs' independence.

CHALLENGES FOR ERNS BEYOND 5 YEARS

- Maybe the expectations have been unrealistic!
 - RD patients have been optimistic to get better treatment but ERNs will be able to tackle only part of the numerous RDs.
 - The aim of ERNs is to harmonise access to and quality of RD care throughout Europe. However, health care is a national issue. This may mean that in spite of the work in ERNs, the offer of treatment, medications and social support for RD patients will not be equal across EU.
 - In addition to RD, the health care systems in EU have other huge challenges relating to, for instance, pandemics, aging populations, drug abuse, climate change etc. How can we continuously demonstrate that investing to RD is important?
 - Maybe having 24 separate ERNs is not an optimal solution: for many goals like building registries, quality issues, reference laboratories etc horizontal elements between ERNs might be necessary.

NOT ONLY CHALLENGES, ALSO HOPES!

