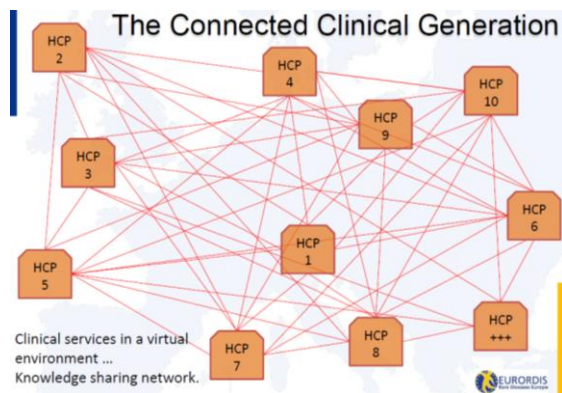


ERN Board of Member States Perspective

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Chances of Member States (MS) with the ERN system with special focus on CE countries

- The build up an **integrated** Trans-European health care system results in an
 - **earlier diagnosis** for patients with rare diseases (PwRD). The No 1. enemy of PwRD is the long delay in setting up correct diagnosis especially in cases **when effective therapy** (e.g. enzyme, factor replacement, anticoagulation, diet etc.) **exists** providing a healthy or near healthy QoL and a average life expectancy.
 - brings bring a **fragmented continent** into **one** while **highly respecting the nation-states** interest and will, also in the field of health care.

Challenges of MS with the ERN system with special focus on CE countries

The new challenges of health care (HC), e.g.

- More **sophisticated and expensive diagnostic and therapeutic measures**
- The cost of **personalized medicine/care**
- **Increased life expectancy** (also for previously fatal disorders like tumors and RDs)

increase its expenses continuously and exponentially - a challenge for all EU countries but an enormous burden for the poorer (like CE) ones.

Challenges of MS with the ERN system with special focus on CE countries

- The HC-System was developed in a different way, including mentality of patients and HC personal
- The CPGs and CDSTs are not or cannot (always) have enough sensitivity to local circumstances
- Language barriers – a special handicap for the elder generations (both MDs and Pts)

However, a challenge might be an advantage as well

- Highly specialized centers usually are eager to have more patients (see e.g. ERNs criteria on minimal patient number)
- The contribution of smaller (e.g. CE) Centers, even when it only means presentation of new cases enhance GCP practice, versatility and cost-effectiveness of these „superspecialized” labs
- It is essential for a trustful and longterm cooperation that each participant (incl. MS and ERN members) must remain equal partners (not as in the Animal Farm, where „All animals are equal, but some animals are more equal than others” (G.Orwell))

MS – the role in tackling obstacles and promote both the role of ERNs and integration (WGNEI)

- Support (political, administrative, financial, organizational, informational etc) to ensure sustainability of ERN full and affiliated members of a specific country
- Help the implementation of related programs like Horizon Europe'2 (announced in the Framework Programme for Research and Innovation, April, 2019), to maximise the impact of EU support to research and innovation
- Facilitate conditions, i.e. reduce bureaucracy in the cooperation of Commission - ERN coordinators – HCPs (ERN members)
- Control and halt unnecessary spending, unfruitful projects

MS – the role in tackling obstacles and promote both the role of ERNs and integration (WGNEI) cont.

- Intensifying interregional/cross border relationships, including patients' and/or experts' virtual and true travel when needed are essential
- Continuous and transparent financial funding mechanism for ERNs virtual (experts') advice
- Recognizing and following ERN HCPs specific needs to enable their efficient participation in ERNs



We should always keep in mind that

A European Reference Network is **more than the sum of its individual parts!**

- Services will include delivery of **specialist advice** on diagnostic, care and treatment, for rare and complex cases.
- Specialist advice will be based on **'collective experience, knowledge and expertise'** generated in the network, which is more than the sum of its individual healthcare providers.