



# Ensuring equitable access across geographical and political borders

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MAY 2018



**Patients with rare diseases** and conditions residing in small countries/peripheral regions MAY and DO face additional access challenges such as:

- Required specialised expertise may be available far away from home and in another country
- Required infrastructure for diagnosis and treatment likewise
- Economies of scale/purchasing and negotiating power
- Excessive travel distances
- Innovative technologies adopted later
- Excluded from research
- Small numbers; small collective voice



**Healthcare professionals** also face additional challenges such as:

- Significant specialist training/training updates need to take place abroad
- Tendency to congregate at general speciality level, e.g. general surgery, general paediatrics
- Unattractive to super-specialise/unable to only work in areas of special interests/risk of loss of expertise
- Exposure to diversity of pathologies may be limited
- Heavy clinical burden
- Disincentives to extra-clinical activities including research/collaborative initiatives



## Health systems face particular challenges such as:

- Significant funds need to be diverted from investment in the local system due to e.g. Rx and tuition abroad
- Risk of 'brain drain' and failure to re-attract specialists training abroad
- Problems with attracting foreign specialists and retaining specialists
- Cannot engage specialists full-time outside general speciality needs
- Smaller amounts of medicines procured at higher prices
- Agents may be unwilling to supply certain medicines and equipment (maintenance issues)



Recent very positive launch of  
**24 European Reference  
Networks**

Networks of healthcare  
providers across EU Member  
States and Norway

Aim to improve access to  
knowledge about and care for  
rare and complex diseases  
and conditions requiring  
highly-specialised treatment



# European Reference Networks





> 300  
HOSPITALS



> 900  
HEALTHCARE UNITS



THOUSANDS OF  
PATIENTS HELPED  
BY 2020

The first intake in  
March 2017 was at  
the level of  
Centres of Expertise  
ONLY



➤ Mandated from the EU legislation on patients' rights in cross-border healthcare (EU Directive 2011/24/EU) – Article 12

➤ One of the 8 objectives of Art. 12:

*2(h) “to help Member States with an insufficient number of patients with a particular medical condition or lacking technology or expertise to provide highly specialised services of high quality.”*



## ERNs by country (May 2018)

Malta – 0

Slovakia - 0

Luxembourg -1 centre; 1 ERN

Croatia – 1 centre; 2 ERNs

Latvia - 1 centre; 2 ERNs

Cyprus – 2 centres; 2 ERNs

Estonia – 2 centres; 3 ERNs

Slovenia – 3 centres; 9 ERNs

Italy (mainland) – 67 centres; majority of ERNs

Italy (Sicily) – 4 centres; 4 ERNs

Germany – 42 centres; majority of ERNs



European  
Reference  
Networks

## Positive developments:

Development of strategy for affiliated partners (AP)

Affiliated partner: will not need to show full attainment of the criteria and conditions and the onus is shifted onto the designating authority of the Member State involved.

The BOMS and the EU Commission is therefore inviting MSs where none of their HCPs may fulfil the criteria for approval as member (CoE) in a given ERN to:

- either designate **in the next months and possibly by Sept. 2018** an **Associated National Centre** for as many of these ERNs as possible;
- or designate **in the next months and possibly by Sept. 2018** a **National Coordination Hub** which will establish a link with all ERNs with which the MS wishes to establish such link

1<sup>st</sup> wave of enrolment of APs only after 2<sup>nd</sup> call for CoE (late 2018/early 2019)



## Points to stimulate discussion

- Patients with rare diseases residing in small countries/peripheral regions/ islands encounter additional challenges, lower opportunities and possible discrimination
- Laudable efforts to improve access to innovative knowledge and treatment need to take these realities into consideration
- Active efforts to counteract these problems need to be sought and undertaken. Otherwise the ‘gaps’ may actually grow larger.
- MT Presidency Proposals for EU Council Conclusions (2017)

*“The Council also adopted conclusions **encouraging a Member States-driven voluntary cooperation between health systems**. This could result in better outcomes for patients and health care professionals, and increase the efficiency and sustainability of health systems. **Voluntary cooperation can help improve patients’ access to treatment, in particular for those patients suffering from rare diseases**. Such cooperation also has the potential to further increase the acquisition of innovative and specialised skills for established professionals within Member States, and access to innovative health technologies”.*

## Options

- Improve connectivity by any means especially by technologies that allow virtual communication
- Increase opportunities for mobility of professionals for pre-determined and repeated periods of attachment at CoE (with safeguards to potential “brain drain”)
- Develop concept of visiting consultants
- Collective negotiation with industry
- Inclusion in research collaboration
- Patient groups to seek/facilitate/support enrolment of patients from smaller countries. Benefit from backing patients’ lobby.



**Thank You**