

RD-Action Joint Action.

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## Participation of EU-13 countries in European Reference Networks

**Introduction:** Rare disease field is an area in which European-wide cooperation may have a major added value. In March 2017, 24 European Reference Networks (ERNs) encompassing more than 900 rare and complex disease-dedicated centres of expertise in more than 300 hospitals, were launched. 25 EU Member States plus Norway decided to authorise the participation of their health care providers (HCP) in the call for ERNs. The aim of an ERN is to tackle complex and rare diseases that necessitate a specific concentration of experience and resources through networking. ERNs were built on a framework of highly diverse health systems, in terms of both organization and legal regulations.

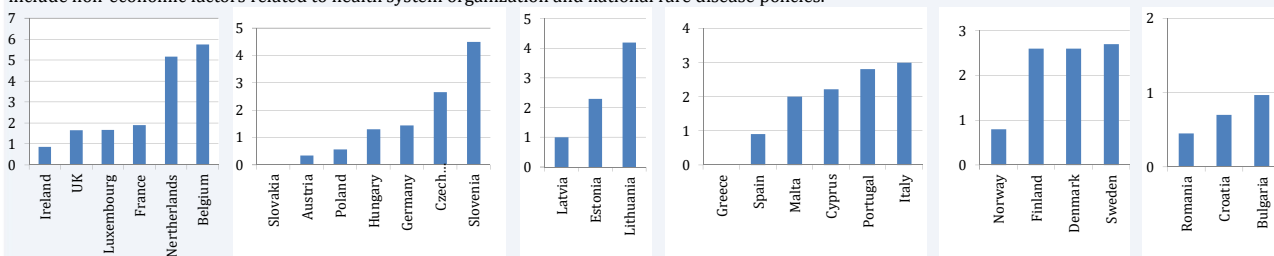
**EU-13 countries** that joined EU in 2004-2013 are home to **one fifth of all EU inhabitants**, hence, one fifth of EU rare disease patients. After joining the EU and experiencing major investments into EU-13 healthcare and research systems, clear growth and development were observed; however, major lags still exist in healthcare and research funding as evidenced by GDP per capita, health expenditure per capita and success rates in FP7 and H2020 programs.

**The aim of this study** – to evaluate regional differences and major factors influencing participation of Member States (MS) in ERNs.

**Methods:** taking into consideration differences in country size, the **number of HCP per million of inhabitants (HCP/mln.)** was selected as the main performance indicator. HCP/mln. was evaluated in relation to **date of EU entrance, country size, GDP per capita, health expenditure per capita, health system structure and organization.** Besides, influence of factors related to rare disease field development were taken into consideration including **national plans/strategies, organization of rare disease centres of expertise and participation in the international activities** as Orphanet and RD-action. The major sources of information for comparisons were European Commission websites, OECD, WHO European Region, European Observatory on Health Systems and Policies publications and data of RD-Action project (Resource on the State- of the Art of Rare Disease Activities in Europe).

**Results:** **12%** (111 HCP) of all HCP participating in ERN are in EU-13 countries. Although HCP/mln. is **1,76** in EU-13 vs. **2,14** in EU-15, substantial differences of HCP/mln. in both groups of countries are observed. Negative correlation with country size is observed: average HCP/mln. in **small MS is 2,16**, medium-sized MS = 2,01, **large MS =1,58**. Although positive correlation of HCP/mln. with economic factors of GDP per capita and health expenditure per capita is very clear, other influential factors include non-economic factors related to health system organization and national rare disease policies.

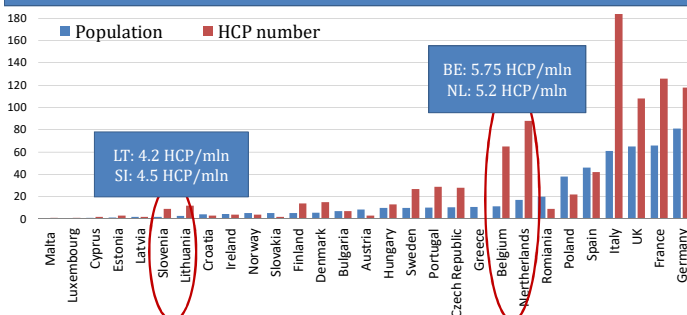
	Population	Health expenditure per capita (2015), www.oecd.org	HCP number in ERNs	HCP/mln.
EU-13	104.8 (20%)	1446	111 (12%)	1.76
EU-15	408.5 (80%)	3467	828 (88%)	2.14
Small MS	18.9 (3.7%)	2312	37 (3.9%)	2.16
Medium MS	137.4 (26.8%)	2639	302 (32.2%)	2.01
Large MS	357 (69.5%)	2755	600 (63.9%)	1.58



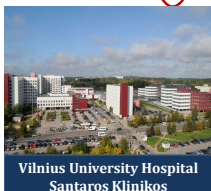
There are **marked differences both across European regions and inter-regionally**, with the highest HCP/mln. in Western Europe (IE, UK, LU, FR, NL, BE; 2,84) and the lowest in Southeastern Europe (RO, HR, BG; 0,7).

**Only two hospitals from EU-13 are in the top 28 of hospitals with the largest numbers of HCP participating in ERNs.**

**Countries with the highest number of HCP/mln. inhabitants: BE, NL, SI, LT.**



Hospital	HCP number	Country
1. University Hospital Leuven	19	BE
2. AO di Padova	18	IT
3. Karolinska University Hospital	18	SE
4. Erasmus MC: University Medical Center Rotterdam	18	NL
5. Assistance Publique-Hôpitaux de Paris, Hôpital Necker-Enfants Malades	15	FR
6. Pediatric hospital Bambino Gesù, Rome	15	IT
7. Radboud University Medical Center Nijmegen	14	NL
8. Great Ormond Street Hospital for Children NHS Foundation Trust	13	UK
9. University Hospital Ghent	12	BE
10. <b>Motol University Hospital</b>	<b>12</b>	<b>CZ</b>
11. Academic Medical Center Amsterdam	12	NL
12. University Medical Center Utrecht	12	NL
13. Charité Universitätsmedizin Berlin	11	DE
14. Universitätsklinikum Freiburg	10	DE
15. Centro Hospitalar e Universitário de Coimbra, EPE	10	PT
16. Hospital Universitari Vall d'Hebron	10	ES
17. University Medical Center Groningen	10	NL
18. University Hospitals Saint-Luc	9	BE
19. Copenhagen University Hospital Rigshospitalet	9	DK
20. Hospices Civils de Lyon	9	FR
21. AOUI Siena	9	IT
22. Central Manchester University Hospitals NHS Foundation Trust	9	UK
23. Assistance Publique-Hôpitaux de Paris, Hôpital Bicêtre	8	FR
24. Klinikum der Universität München	8	DE
25. Fondazione IRCCS CA'Granda Ospedale Maggiore polyclinic - Milan	8	IT
26. <b>Vilnius University Hospital Santaros Klinikos</b>	<b>8</b>	<b>LT</b>
27. Leiden University Medical Center	8	NL
28. Birmingham Children's Hospital NHS Foundation Trust	8	UK



**Conclusion:** both economic and non-economic factors may be relevant to Member States' participation in the first stage of ERN development.

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