



LIETUVOS RESPUBLIKOS
SVEIKATOS APSAUGOS MINISTERIJA

STRATEGIC VALUE OF EUROPEAN REFERENCE NETWORKS FOR LITHUANIA

2015-10-09

Lisboa

Cross-border benefits

The Directive 2011/24/EU sets the principles of patients' rights in cross-border health care. The one of the ultimate goals of establishing ERN is... to facilitate improvements in diagnosis and the delivery of high-quality, accessible and cost-effective healthcare for all patients with medical condition requiring a particular concentration of expertise in medical domains where expertise is rare (Article 12-2c; 2011/24/EU)

We all are different, but...

- ❖ Despite cultural and national diversity and numerous modes of thought we can speak the same language on the patient-centered platform where professionals meet to exchange their experience, knowledge and capacities.
- ❖ The call to join European reference networks will be the call to speak and think the same language while providing highly specialized care to patients, suffering rare or low prevalence complex diseases or conditions on cross-border background.

The main emphasis of interaction of ERNs

As ERNs are being launched to help professionals and centers of expertise in different countries to share knowledge, there are three key points what they should serve for:

1. apply EU criteria to tackle rare diseases requiring specialized care
2. serve as research and knowledge centres treating patients from other EU countries
3. ensure the availability of treatment facilities where necessary - expertise should “travel” to the patients, but it should be possible for patients to travel to centers, if necessary

Preparation to establish ERN

- Different levels of preparation:
- Those MS already established mainly informal national or international networks (however for one or few rare diseases) and share information and concentrate patients (mainly high population MS – wish and/or have ability to coordinate ERN)
- Those MS that started preparation (setting standards for rare diseases, designation of centers of expertise at national level etc.) to join ERN (majority MS – wish to join ERN in certain groups of rare diseases)
- Those MS that have no abilities (due to lack of expertise, equipment, concentration, low population etc.) to become fully recognized centers in ERN, however wish to have access to high quality healthcare (some MS – wish to be associated members of ERN)

What emphasis should we stress concerning ERNs

- ❖ **Less but not the worse.** Small countries, with several millions of residents, are capable of demonstrating sufficient expertise, valuable experience and sustainable and highly specialised provision of health care services to patients. Small countries should not be excluded from equal and competent participation in ERNs due to specific provisions related to number of patients, volume of activity, ultra sophisticated infrastructure, annual turnover and other subjective factors;
- ❖ **Rearrange before credible exchange.** We do not see ERNs without a possibility of personal data exchange. Deployment and development of electronic data exchange solutions on cross-border dimension requires a legal shift in order to secure equal or more or less convenient patient data exchange mechanisms within the EU countries;

What emphasis should we stress II

❖ Considered start encourages us infallible continuity.

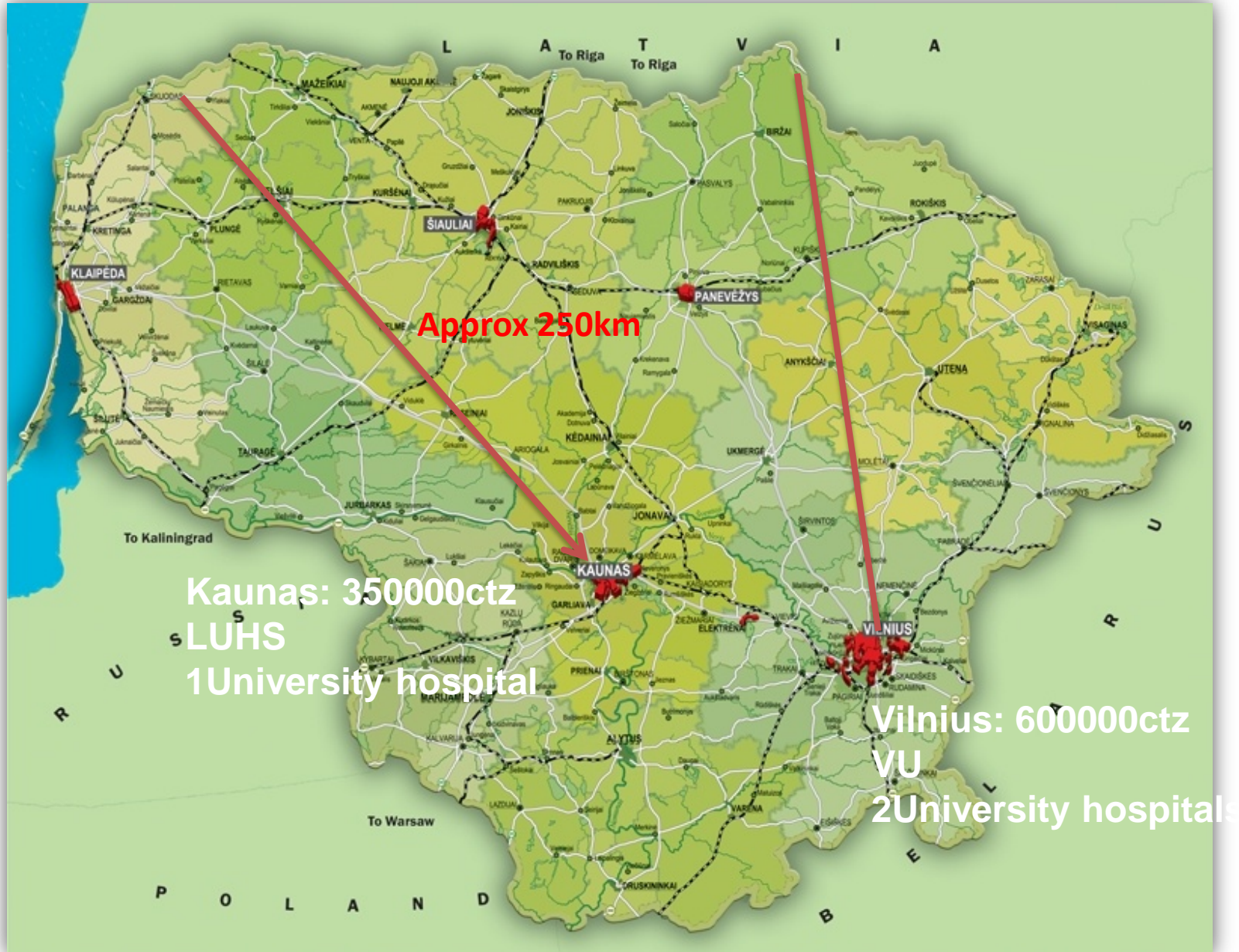
1. Though ERNs do not mean new legal entities and should not contribute any vast initial expenses. The administration structures shall demand additional expenses. Financial aspects should be worked out.
2. Operation schemes of ERNs should be clear, transparent and fair.
3. Selection procedures of applicants, wishing to join ERNs, should include experts, delegated by all member states.

Small MS

- Malta Luxembourg Cyprus - below 1mln
- Estonia Latvia Lithuania – 1-3mln
- Croatia Ireland – 3-5mln

- All other MS – more than 5 mln

Lithuania ~ 3 000 000 citizens



What do ERNs mean to Lithuania

Lithuania has designated four national centers of reference in the fields of **neurosurgery, oncohematology, endocrinology and congenital rare heart diseases**. Most of Lithuanian centers of expertise in highly specialized care:

- ❖ are involved in multidisciplinary work;
- ❖ are involved in clinical and scientific research;
- ❖ issue best practice guidelines;
- ❖ develop and deploy e. health solutions;
- ❖ ensure patient centered approach;
- ❖ organize education and training;
- ❖ are capable of exchanging knowledge, cooperate and network.

Generally, they are already acting as centers of reference, despite the fact that they are not labeled as such.

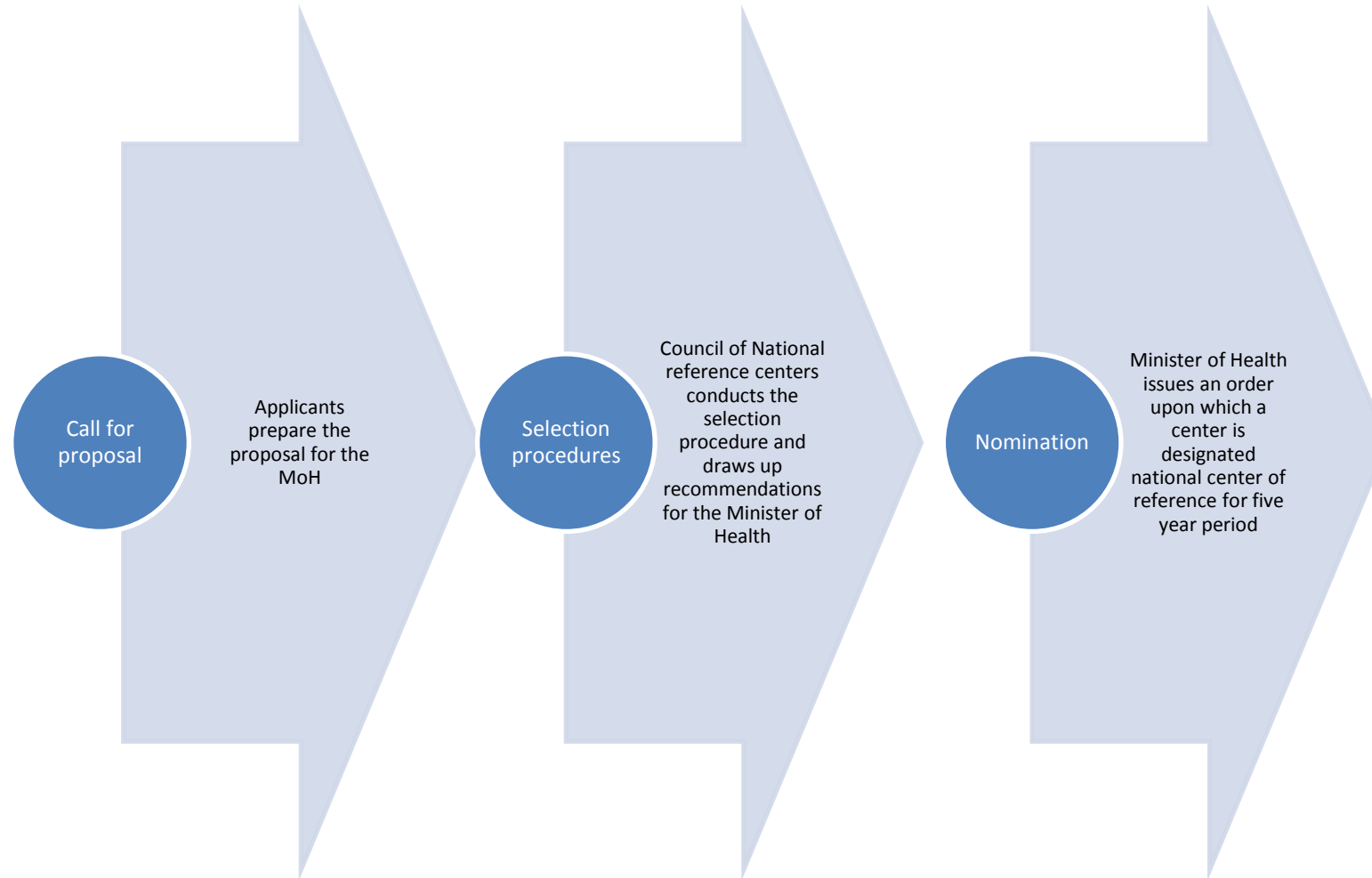
Legal Background

- ❖ EU legislation (Directive 2011/24/EU; Commission Delegated Decision of 10 March 2014 setting out criteria and conditions that European Reference Networks and healthcare providers wishing to join a European Reference Network must fulfill);
- ❖ National provisions on specific issues (National action plan on rare diseases and National plan on the optimization of services of neurosurgery for the period of 2015-2020);
- ❖ National criteria and procedures of selection of national centers of reference.

Body in charge of selection procedures

- ❖ Council of National reference centers, designated by the order of the Minister and combined of 6 members:
- ❖ Two representatives of MoH (Chair and Deputy Chair);
- ❖ Two representatives of academia: Vilnius university (Vilnius) and Lithuanian University of Health Sciences (Kaunas)
- ❖ Two representatives of University hospitals
- ❖ Officially designated members of the Board of European Reference networks are participating without a right of a vote

Scheme of the selection procedure



Main principles of selection procedure

- ❖ The main principle of designation of national reference centers is:

the interaction and partnership rather than rivalry of centers of high expertise

- ❖ Centers of high expertise are encouraged to consent on designation of one national reference center in certain area of practice. Other centers may collaborate under the conditions of joint partnership.
- ❖ In case the consent cannot be reached, the applicants are subject to a procedure of comparison according to wide number of operational and clinical indicators.

Expectations

- First of all – ERN is the possibility for Lithuania to reinforce provision of health care services in the area of rare or complex diseases:
- Cooperation – setting and renewal of health care standards, sharing expertise.
- Access to necessary expertise, which is unavailable across the country
- Training of experts
- Joint Clinical and Basic Research

Expectations

- ❖ Reference networks should conduct a synthesis of knowledge and expertise which are pooled in different centers of expertise across Europe.
- ❖ There is no sense of exchanging knowledge among players with exactly the same list of capacities. Everyone has to be ready to give and take the advantage at the same time. For instance, if one member of a network is more advanced than the other in a certain case (i.e. dealing with certain surgical interventions for ultra low prevalence conditions), he will provide the expertise. But we have to take it into account that the other member might have more experience in other cases.

Strategic value of centers of reference for Lithuania

- ❖ Firstly to provide a rating scheme that enables consumers to identify the appropriate health-care resource for their case. The objective of a rating scheme is to guide consumers to trustworthy health information and empower them to select high-quality services for referral.
- ❖ Secondly, to enable health-care managers identify where best to allocate financial resources. Designated centres have both rights and duties that require additional staff and resources - designation as a centre of reference increases referral rates and the number of requests for expert opinions. In addition, centres of reference must be involved in clinical research, issue best practice guidelines and produce information leaflets for patients.
- ❖ Ability to ensure maximum spectrum of health care services needed by the patients. Opportunities to build capacities without physical „brain drain“

Primary goal for Lithuania in the area of ERN

- ❖ is to join ERN in specific areas of Rare diseases where the high level of expertise and resources are concentrated in the country.
- ❖ this is about acting jointly at the level which is meant for the best effect while coping with the burden of rare diseases.
- ❖ this is about caring, sharing and curing - the catchword of the ERNs say so. This is about giving and taking altogether, not only one or the other.