EXPERT PANEL ON EFFECTIVE WAYS OF INVESTING IN HEALTH

Request for an opinion: Application of the ERN model in European cross-border healthcare cooperation outside the rare diseases area

Background – Rationale

Member States have the interest and responsibility to give their citizens the best possible health services. This has led to different arrangements for cooperation between the European countries, as joint work in healthcare can bring clear added value. The European Union, on the basis of Article 168 of the TFEU plays an important role in complementing and supporting national health policies, encouraging cooperation among Member States and promoting coordination between their programmes. This general mandate was further defined in Directive 2011/24/EU on the application of patients’ rights in cross-border health care.

The European Reference Networks\(^1\) are a prime example of structured and voluntary collaboration among the EU Member States in the field of healthcare. These cross-border networks bring together healthcare providers across Europe to tackle rare, complex and low prevalence diseases that require highly specialised healthcare and concentration of knowledge and resources. The ERNs give access to a much larger, cross-border pool of expertise and knowledge, increasing the chances of patients receiving the best advice to treat and diagnose their diseases. By gathering a large pool of patient data, they will, in the longer term, facilitate large clinical studies to improve the understanding of diseases or support the development of new medicinal products. The Commissioner Andriukaitis highlighted the wide cooperation opportunities of the ERNs, referring to them as a backbone for building a European health data eco-system.\(^2\)

Although the Directive references in particular to rare diseases, it is suggested that other conditions requiring specialized resources or expertise could also benefit from the idea of networking to provide high-quality and cost-effective care\(^3\). Could the experience gained in cross-border collaboration on rare diseases be transferred to other health topics? Therefore it would be important to assess what could be the potential areas to tackle and what are the existing possibilities.

Rare diseases affect 6-8% of the population and as a group are an important public health problem. Many of the more prevalent diseases with the highest mortality rates in Europe, such as cardiovascular diseases (accounting for 34% of all deaths among men and 40% among

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\(^1\) [https://ec.europa.eu/health/ern/work_en](https://ec.europa.eu/health/ern/work_en)


\(^3\) [http://www.euro.who.int/__data/assets/pdf_file/0004/184738/e96805-final.pdf?ua=1](http://www.euro.who.int/__data/assets/pdf_file/0004/184738/e96805-final.pdf?ua=1)
women), cancer (30% men, 24% women) and respiratory diseases (9% men and 8% women)\(^4\), are successfully treated at national level, nonetheless European cooperation could still bring improvements in outcomes. There are also specific treatment or diagnostic challenges (genetic testing, PET) as well as regional cooperation difficulties, where cross-border collaboration could bring added value\(^5\). The Council Conclusions in June 2017 suggested that the ERNs could, within their current scope, assume a role in highly specialised training and continuous professional development for health professionals\(^6\).

In the longer term, such new modes of European cooperation could be essential in shaping the healthcare delivery in the European Union.

**Terms of Reference for the Expert Panel on Health**

The Expert Panel's opinion on the application of the ERN model outside the rare diseases area would help to prepare future calls for new networks, by presenting the possibilities, outcomes and expected difficulties of a broader cooperation.

The Expert Panel will be requested to analyse the following:

(a) What are the areas that can benefit most from the ERN model of cross-border cooperation? Should the selection process take into account:
   - the nature of disease (prevalence, complexity),
   - resources of the geographical area (small countries, remote areas, border regions),
   - medical intervention (treatment method or product),
   - specific goal of such a cooperation (e.g. creating new medicine)?

(b) The panel should address as well aspects related to the implementation of the ERN model and advise on the different options for the long term nature of new networks. Should the ERN model be used as a whole (covering diagnosis and treatment, research, training, knowledge generation…) or only include specific modules of collaboration depending on the need (e.g. only data gathering for Artificial Intelligence or genetic testing)?

(c) How would national health systems integrate such networks into their national framework? What are the difficulties to expect at national level? What would be the best national approach in the aspect of referral, financing and changes required in national legal systems?

**Timing**

Ideally the opinion of the Panel should be finalised by mid-2018.

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