European
Commission

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

Share. Care. Cure.

European
Reference
Networks
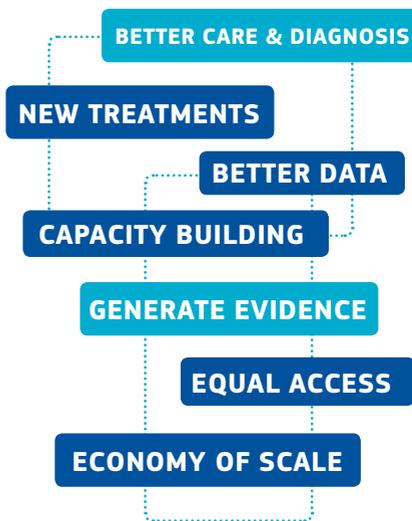
Health

WHAT'S AN ERN?

European Reference Networks (ERN) are **virtual networks** involving healthcare providers across Europe. They aim to tackle complex or rare medical diseases or conditions that require highly specialised treatment and a concentration of knowledge and resources. To review a patient's diagnosis and treatment, ERN coordinators will convene a "virtual" advisory board of medical specialists across different disciplines, using a dedicated IT platform and telemedicine tools. This way it is **the medical knowledge and expertise that travel rather than the patients**, who have the comfort of staying in their supportive home environments.

EACH YEAR THOUSANDS OF PATIENTS WILL BE HELPED BY ERNs

BETTER CARE & DIAGNOSIS

NEW TREATMENTS

BETTER DATA

CAPACITY BUILDING

GENERATE EVIDENCE

EQUAL ACCESS

ECONOMY OF SCALE

HOW WILL ERNS HELP PATIENTS?

Between 6 000 and 8 000 rare diseases affect or will affect an estimated 30 million people in the European Union. Many of these rare diseases cause chronic pain and suffering, and a number of them can be life-threatening. The negative impact on the quality of life of affected patients, many of whom are children, is significant.

An unfortunate feature of rare diseases and complex conditions is the scarcity and fragmentation of specialist knowledge, which is often not available in the patient's region or country. Many patients therefore do not find a satisfactory explanation for their symptoms or the necessary knowledge on treatment options. Consequently, many patients and their families rely on the internet to search for doctors and healthcare providers with the expertise to give them the best possible chance of survival.

By **consolidating** knowledge and expertise scattered across countries, the ERNs will give healthcare providers access to a much larger pool of expertise. This will result in better chances for patients to receive an **accurate diagnosis** and advice on the **best treatment** for their specific condition.

ERNs are not directly accessible to individual patients. However, with the patients' consent and in accordance with the rules of their national health system, patient case can be referred to the relevant ERN member in their country by their healthcare provider.

EUROPEAN COOPERATION

Working together with Member States, the medical community and patient organisations, the Commission has taken a leading role to develop this unique ERN model: for the first time in healthcare, a formal structure of voluntary collaboration between healthcare providers across the EU has been created for the direct benefit of the patient.

The first wave of ERNs already covers the majority of disease groups, including bone disorders, haematological diseases, childhood cancer and immunodeficiency.

> *Hearing that your 15-year-old daughter has a disease that is untreatable because her doctors have never seen anything like it and do not know what treatment could help save her life would be a nightmare for any parent.*

PATIENTS

NATIONAL HEALTH-CARE PROVIDERS

SPECIFIC ERN

CLINICAL GUIDELINES

RESEARCH & INNOVATION KNOWLEDGE

GENERATING & SHARING EVIDENCE

TRAINING & E-LEARNING

TREATMENT

ADVICE

› 300 **HOSPITALS**

› 900 **HEALTHCARE UNITS**

THOUSANDS OF PATIENTS HELPED BY 2020

CROSS-BORDER HEALTHCARE DIRECTIVE

ERNs are being set up under the 2011 Directive on patients' rights in cross-border healthcare. This Directive also makes it easier for patients to access information on healthcare and thus increase their treatment options.

NEXT STEPS

The first ERNs will be up and running in 2017. Further calls for new healthcare providers to join the existing Networks, as well as calls for new ERNs will follow.

Over the next five years, as the ERNs reach full capacity, thousands of EU patients suffering from a rare or complex condition can expect to benefit.

ec.europa.eu/health/ern