



Endo-ERN

European Reference Network  
on Rare Endocrine Conditions

## What are European Reference Networks?

Virtual expert networks that aim to tackle complex or rare diseases. The cooperation between expert healthcare centers will cause the expertise to travel, rather than the patients.

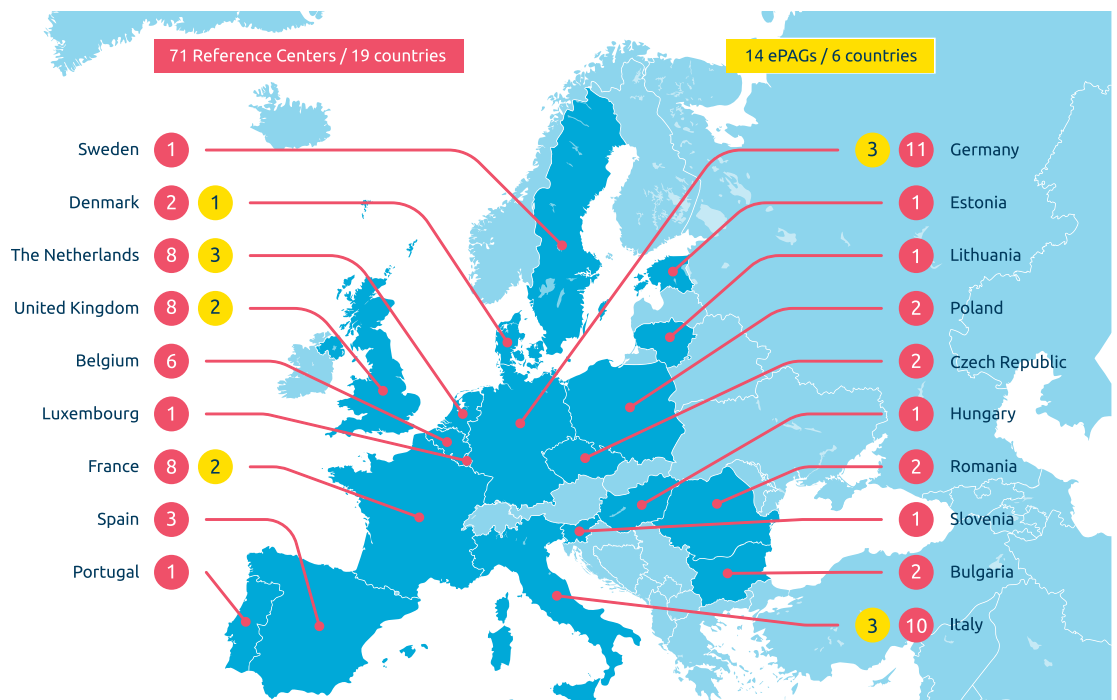
This is possible with the use of the CPMS (Clinical Patient Management System), a virtual consultation platform, that will be operational in 2018.

## Which (groups of) diseases are covered by Endo-ERN?

- 1 Adrenal
- 2 Disorders of Calcium & Phosphate Homeostasis
- 3 Genetic Disorders of Glucose & Insulin Homeostasis
- 4 Genetic Endocrine Tumour Syndromes
- 5 Growth & Genetic Obesity Syndromes
- 6 Pituitary
- 7 Sex Development & Maturation
- 8 Thyroid

## Where can you find us?

Endo-ERN has collaborating reference centers in 19 countries and patient advocacy group representatives (ePAGs) from 6 countries.



Contact  
Endo-ERN Coordinating Center:  
Leiden University Medical Center  
The Netherlands  
info@endo-ern.eu  
www.endo-ern.eu



Check out [www.endo-ern.eu](http://www.endo-ern.eu) for more information!



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## What can we do for you?

Endo-ERN's mission is to reduce and ultimately abolish inequalities in care for patients with rare endocrine conditions in Europe.

Increase awareness amongst general public and health care professionals by:

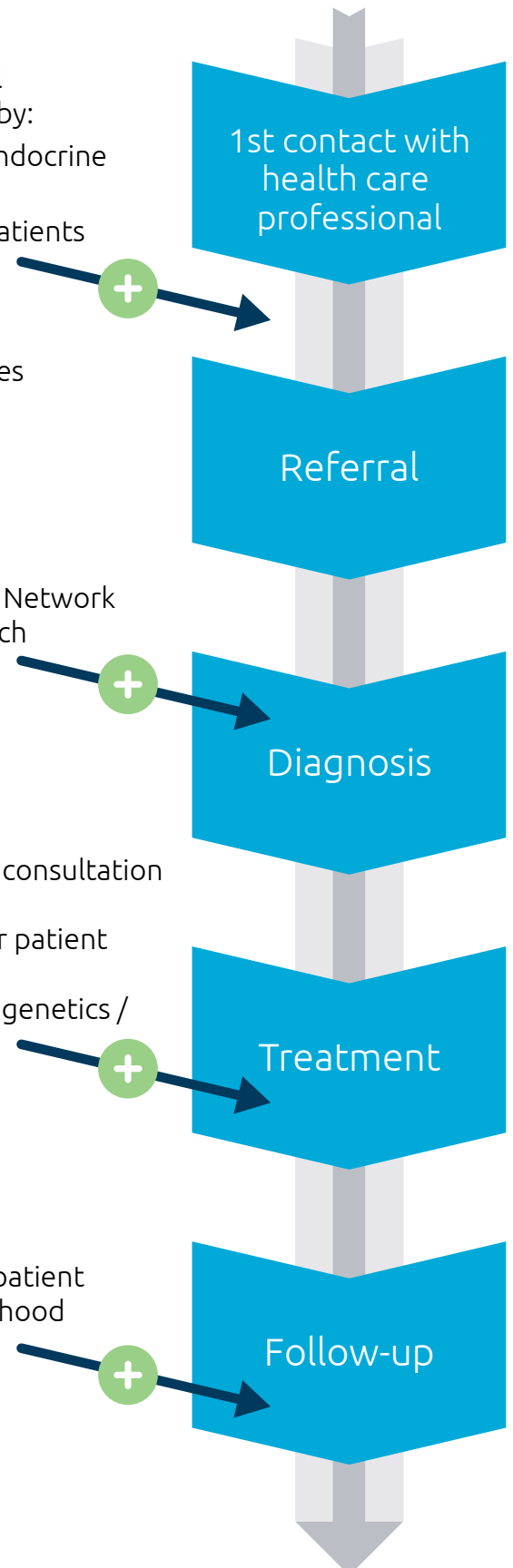
- Dissemination of information on endocrine conditions
  - Collaboration of Network with patients associations
  - Conferences
  - Network website
  - Actions towards health authorities

- Guidelines
- Individual care plan defined by the Network
- Facilitation of clinical trials / research

Shorten delay in diagnosis by:

- Multidisciplinary diagnostic expert consultation
- Use of telemedicine
- Patient pathway monitoring (tracer patient method)
- Access to specific diagnostic tools: genetics / lab-hormonal measurements

- Education of patients
- Instructions to GP's following the patient
- Transition from childhood to adulthood
- QoL surveys
- Training of delegates
- Prevention of complications and co-morbidities



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