

Hospital's management and ERNs



European
Reference
Networks

Share. Care. Cure.

LUMC Leiden, The Netherlands

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4TH ERN CONFERENCE
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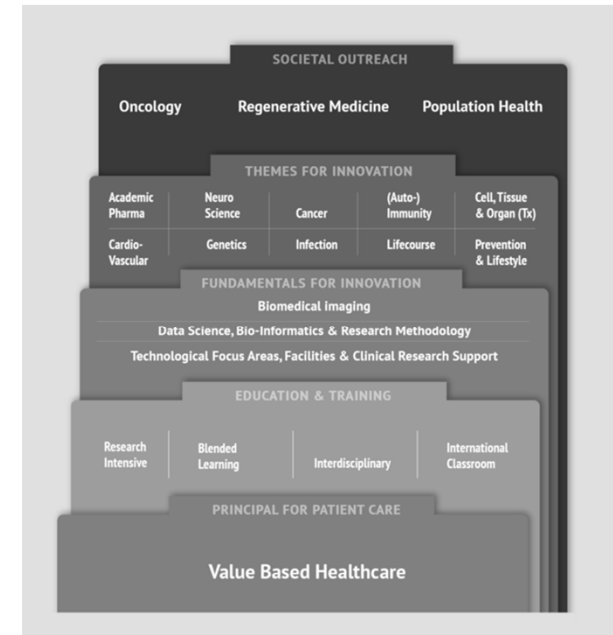
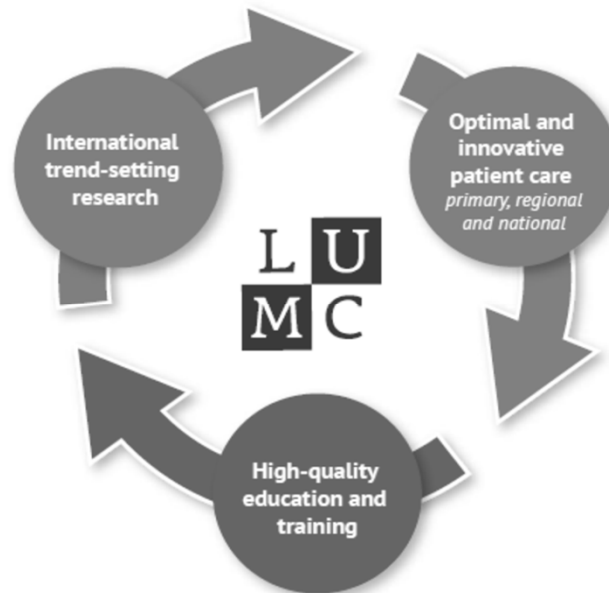


Disclosure

*I have no actual or potential conflict of interest
in relation to this program/presentation*

Leiden –UMC: Center for research, patient care and education

'As an innovator, the LUMC aims to improve healthcare and people's health'.



Prerequisites for Innovation:

- VDHC & DDHC
- National recognized rare disease expert centers and
- Our role in ERN

Hospital management

ERN membership: Added value for patients

- Scarce expertise and specialist knowledge
- Better quality of care across the EU
- Decreasing health inequalities
- A more efficient, accessible and resilient healthcare system



Hospital management

ERN membership: Added value for Health Care Providers

- ❑ Platform for the development of guidelines, training and knowledge exchange
- ❑ Clinical studies by gathering a large pool of patient data
- ❑ Best practice sharing:
 - A strong network of like-minded experts
 - A network to advance innovation in healthcare (e.g. VDHC, eHealth)



Imagine if the **best specialists** from across Europe could join their efforts to tackle **medical conditions** that require **highly specialised healthcare** and a concentration of knowledge and resources.

That's the purpose of the **European Reference Networks** and it's becoming a reality.

Share and enhance your expertise. Talk with your colleagues. Join a **Network proposal** in early 2015.

More information at ec.europa.eu/join-ern

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Dutch Federation of University Medical Centers

Role in National recognized expert centres

- ❑ The Netherlands has an official National Rare Diseases Plan
 - The designation of Expert Centres has been fully implemented by decree of the Ministry of Health.
 - The national criteria for designating a Expert Centre is fully based on the EUCERD-criteria.

- ❑ NFU, Federation of 8 University Medical Centres in the Netherlands
 - Acts on behalf of Ministry of Health
 - Orphanet Nederland (Science)
 - VSOP (Patient Centeredness)



ERN coordinator:

- **Endo-ERN** - ERN on endocrine disorders

Other ERN-memberships:

- **ERN-BOND** - ERN on bone disorders
- **ERN-EYE** - ERN on eye diseases
- **ERN-LUNG** - ERN on respiratory diseases
- **EURACAN** - ERN on adult cancers (solid tumours)
- **EuroBloodNet** - ERN on haematological diseases
- **EURO-NMD** - ERN on neuromuscular diseases
- **ReCONNET** - ERN on connective tissues & musculoskeletal diseases

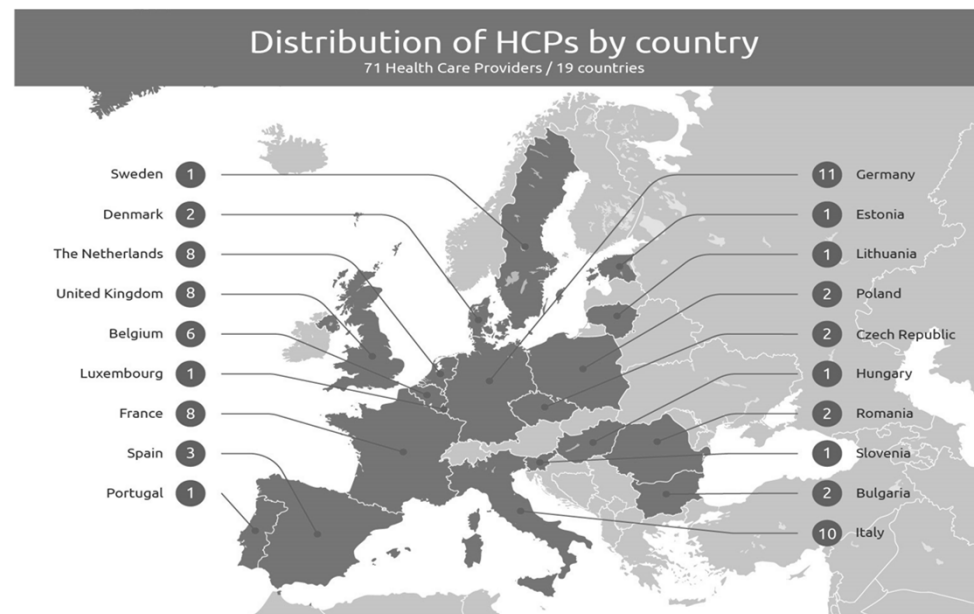


Hospital Management: an example of best practice

Endo-ERN

- ❑ All inclusive
 - ✓ broad thematic network to ensure that all patients with rare and/or complex conditions have ‘a home’
 - ✓ inclusivity intrinsic part of ERN (HCP and patient)

- ❑ Expertise across the entire lifespan
 - ✓ endorsed by European Pediatric and Adult Scientific Societies
 - ✓ patient representation ensured in governance

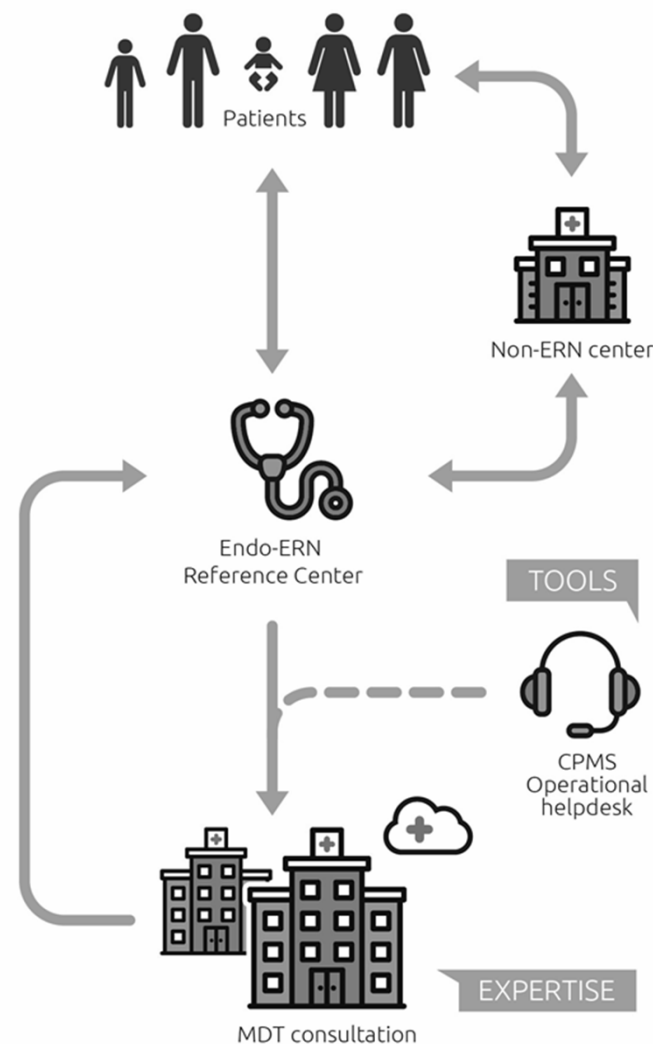


Endo-ERN's mission is to reduce and ultimately abolish inequalities in care for patients with rare endocrine disorders in Europe, through facilitating knowledge sharing and facilitating related healthcare and research. Endo-ERN provides equality between paediatric and adult patients. Ultimately, Endo-ERN will result in the best possible care for every patient with a rare endocrine condition.

Hospital management: virtual consultation

Key Priority: Clinical Patient Management System

- ❑ Started with LUMC Endo-ERN in order to have a connection of locally collected data (e.g. from HiX) as input for the CPMS
- ❑ Short-term solution (manually) has been realised and is 'in use'
- ❑ Long-term solution is 'under construction': automated solution based on principles of 'Registration at the Source' .
- ❑ Promoted by national funds (CITRIEN) to stimulate working in a cross border network.
- ❑ Promoted solution for Endo-ERN-colleagues within Europe.



Hospital management

Key Priority: Quality Assurance Patient Centered Integrated Care



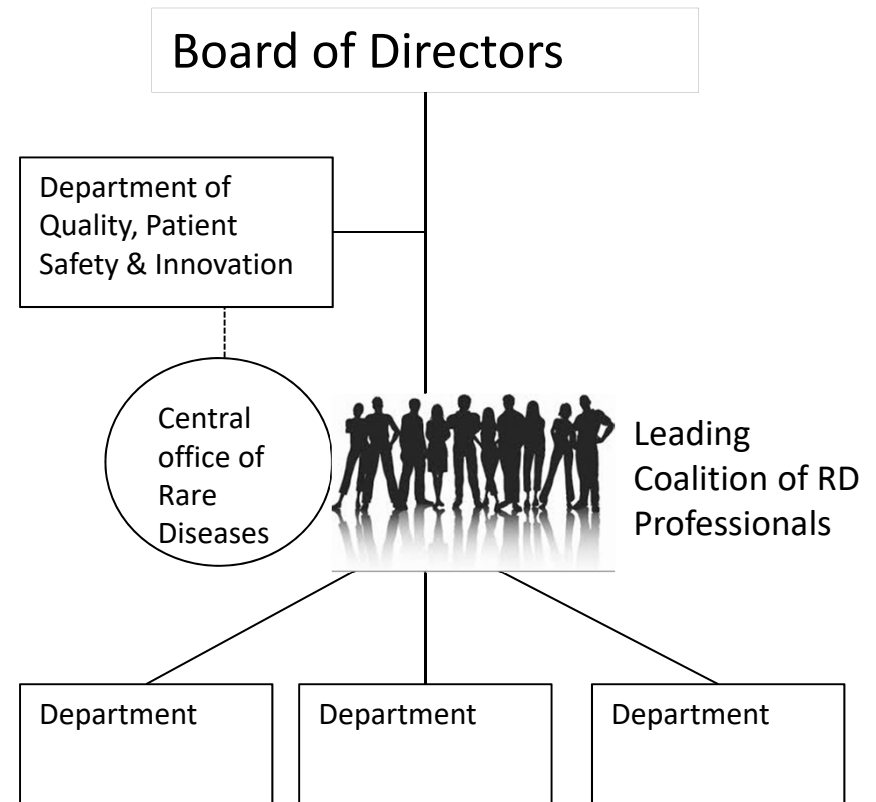
- Started with LUMC Endo-ERN
- Current experiences learn that the role of a case manager in this process is crucial for a high response rate from patients
- An appointment with patients to discuss the outcome of the measurement(s) give a response rate of almost 100%.
- Response of patients on the measurements also give the clinicians excellent opportunities to tailor treatment to individual patients.
- Results in a more efficient treatment process

Hospital management

Key Priority: Providing common tools

Foundation of a LUMC central office Rare Diseases:

- ❑ Process to obtain and maintain the status of national recognized expert centre rare disease
- ❑ ERN application and audit process
- ❑ Coordinates IT, databases, interoperability, etc. to tailor the needs for Rare Disease Expert Centres
- ❑ Policies on LUMC wide themes such as biobanking
- ❑ Sharing best practices, organizing (in-house) symposia to support the interconnection of the ERN's, national centres and their members.



Hospital management

Key Priority: bridging VDHC, DDHC and AI

Integrated care => multidisciplinary teams (IPU) in a collaborative network



Leading coalition of professionals in Rare Diseases



Leading coalition of professionals in:

- value driven health care &
- data driven health care &
- artificial intelligence

Hospital management

Keypoints to address

- ❑ Shared responsibility:
 - EC (DG Santé)– Board of MS – Board of Directors Health Care Providers

- ❑ Appeal to CEO HCP's: Prioritize the support of your health professionals to care for patients with rare diseases through ERN's

- ❑ Appeal to CEO HCP's & Member States: Support functional application of CPMS in all HCP; enroll rare disease cases for which expertise is needed through the CPMS Platform
 - NL: the need for one interoperable electronic patient record system

- ❑ Appeal to Member States: New models for compensation schemes for cross border (virtual) consultation
 - NL: specific role health insurance companies
 - Suggestions Coordinators

