Directive 2011/24/EU of patients’ rights in cross-border healthcare

- Right to choose and be reimbursed for healthcare provided by public or private providers located in the EU
- More transparency about their rights, treatment options or, the quality and safety levels of healthcare providers

- **Thus:** maximum focus of ERNs on transparency and dissemination of expertise is key to make an individualized choice for best care
Prerequisites for the ideal ERN

- broad thematic network to ensure that all patients with rare and/or complex conditions have ‘a home’

- patient centered

- expertise/added value across the entire lifespan

- added value evident for all patients

- bottom-up-top-down development, shaping, and governance

- inclusivity intrinsic part of ERN (HCP and patient)
The Trajectory towards Endo-ERN

Lübeck-Leiden-Boston meetings:
- Defining the European Landscape of Rare Endocrine Conditions (Main Thematic Grouping)
- ESE-ESPE Decision on ERN Coordination & Governance

16 March 2016
2 April 2016
7 April 2016
Endo-ERN
Expert multi-disciplinary care throughout life

diabetes
transitional care
parathyroid
pituitary
adrenal
thyroid
obesity
growth
puberty
DSD
endocrine tumours
Governance Rare Endocrine Conditions (Endo-ERN)

**Board** (Adult and Paediatric Endocrinologists)
- Chair (coordinator, 1 vote)
- Vice-chair (deputy coordinator, 1 vote)

**Steering committee**
- 3 chairs per Main Thematic Group and per Work Package
  (Adult and Paediatric Endocrinologists and ePAG)
  (1 vote per Main Thematic group and per Work Package)

**Management board**
- (General Assembly, annual meeting)
  Health Care Provider representatives (1 per HCP, 1 vote per HCP)

**Advisory Board**
- (no votes)
  - ESE & ESPE representatives
  - Representatives of other European Endocrine Societies
  - National representatives (National Coordinators)

**National Coordinator**
- National representative
- If issues arise
- linking pin
- dissemination of expertise
Endo-ERN Mission: defined in 5 WPs to be delivered in 8 MTGs

- **MTG1**: Education & Teaching
  - **Phase I**: Survey and gap analysis
  - **Phase II-III**: Training through workshops, cases and online platforms
- **MTG2**: E-Health & ICT
  - **Phase I**: Survey and resource analysis
  - **Phase II-III**: Develop SOP, TECs, address gaps where clinical utility is high
- **MTG3**: Research & Science
  - **Phase I**: Survey and analysis of research needs expertise
  - **Phase II-III**: Stimulate new research, enable spread of expertise and patient involvement
- **MTG4**: Quality of Care & Patient View
  - **Phase I**: Survey and analysis, definition of outcome measures
  - **Phase II-III**: Improvement guidelines, harmonise care across EU
- **MTG5**: Diagnostics & Laboratory Analysis
  - **Phase I**: Develop QC and accreditation measures
  - **Phase II-III**: Build network, building of network tools

- **MTG6**: Adrenal
- **MTG7**: Disorders of Calcium & Phosphate Homeostasis
- **MTG8**: Genetic Disorders of Glucose & Insulin Homeostasis
- **MTG9**: Genetic Endocrine Tumour Syndromes

- **MTG10**: Growth & General Obesity Syndromes
- **MTG11**: Pituitary
- **MTG12**: Sexual Development & Maturation
- **MTG13**: Thyroid
Endo-ERN: Added value for patients

Patient Pathway

1st contact with health care professional

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

Referral

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

Diagnosis

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

Treatment

Follow-up

- Education of patients
- Instructions to GPs following the patient
- Transition from childhood to adulthood
- QoL surveys
- Training of delegates
- Prevention of complications and co-morbidities
Distribution of HCPs by country

71 Health Care Providers / 19 countries

- Sweden: 1
- Denmark: 2
- The Netherlands: 8
- United Kingdom: 8
- Belgium: 6
- Luxembourg: 1
- France: 8
- Spain: 3
- Portugal: 1
- Germany: 11
- Estonia: 1
- Lithuania: 1
- Poland: 2
- Czech Republic: 2
- Hungary: 1
- Romania: 2
- Slovenia: 1
- Bulgaria: 2
- Italy: 10
European network of Expertise Centers: how can it work optimally?

- Shorten delay in diagnosis:
  - Earlier referral
  - All required experts together
  - Best diagnostic techniques
- Best treatment
- Best education of all involved
European Network of expertise centers: patient travels to expertise?

ENDO-ERN
71 expertise centres

patient with rare endocrine condition

patient with rare endocrine condition

patient with rare endocrine condition

patient with rare endocrine condition

patient with rare endocrine condition

patient with rare endocrine condition
European Network of expertise centers: expertise travels to the patient!
ERNs should inter-connect with national and regional networks

**National Coordinator** for Rare Endocrine Conditions
- France (since 2005: prof J. Bertherat)
- Italy (2016: prof A. Colao)
- the Netherlands (2017: prof G. Valk)
Conclusions

Both Inclusivity and Dissemination of expertise is key in optimal Network Management and Governance
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Evolving role of patients not only in reference to choice of best health care provider, but also in shared-care and shared-decision making, and thus in Management & Governance
Conclusions

Both Inclusivity and Dissemination of expertise is key in optimal Network Management and Governance

Evolving role of patients not only in reference to choice of best health care provider, but also in shared-care and shared-decision making, and thus in Management & Governance

The challenge is to make this succesful with the available funds, but:
- everybody is very much engaged and highly committed
- there is enormous awareness for why this is so important, and that’s why so many are altruistic in doing so
- Fantastic framework of MTG en WPs with the best experts being in the lead.