Personalizzazione delle cure

The example of European Reference Networks (ERNs)

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Health and Digital Executive Agency (HaDEA)

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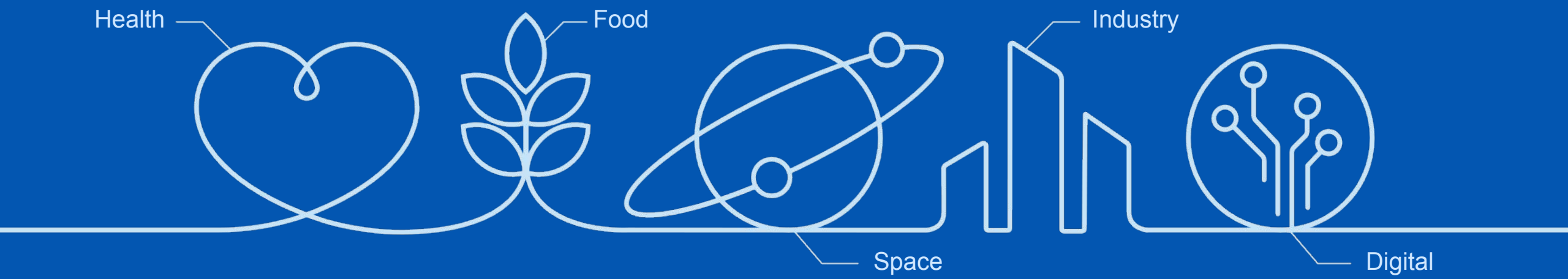
Who we are and what we do

European Commission

Our Agency

The European Health and Digital Executive Agency (HaDEA) implements European programmes and initiatives on behalf of the European Commission, by managing projects that are related to health, digital, food, industry and space.



HaDEA works together with and on behalf of DG SANTE, HERA and RTD to implement funding programmes for health

SANTE

European Commission

HERA

RTD

Programmes

EU4Health

€4.7b*

Horizon Health

€5.4b*

including €1.3 billion under Next Generation EU

HaDEA

Implementation

*estimated budget allocation in current prices

European Commission

EU4HEALTH PROGRAMME

Largest ever EU financial commitment to improve and foster health in Europe.

€5.3 billion (4.7 billion managed by HaDEA) available through:

- Open calls for **project grants**
- Open calls for **tenders**
- **Operating grants** to NGOs
- **Direct grants** and **contributions agreements**

European Commission

Personalised care: Projects we support

Zoom into the European Reference Networks (ERNs)

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Rare Diseases and ERNs

Did you know?

Between **27** and **36** million people in the EU live with a rare disease.

Between **6 000** and **8 000** distinct rare diseases are estimated to exist today in the EU.

Whilst one rare disease may affect only a handful of patients, another may touch as many as **245 000.**

Around **80%** of rare diseases are of genetic origin and **70%** already start in childhood.

European Commission

European Reference Networks

- Established under **Directive 2011/24/EU on patients' rights in cross-border healthcare**, the European Reference Networks are **virtual networks of healthcare providers** specialised in treating patients with rare, low prevalence and complex diseases

- **24 ERNs** were **launched** in March **2017** with continued **funding from the EU**

- This includes **1613 specialised centres** and **380 hospitals** in 27 EU Member States and Norway

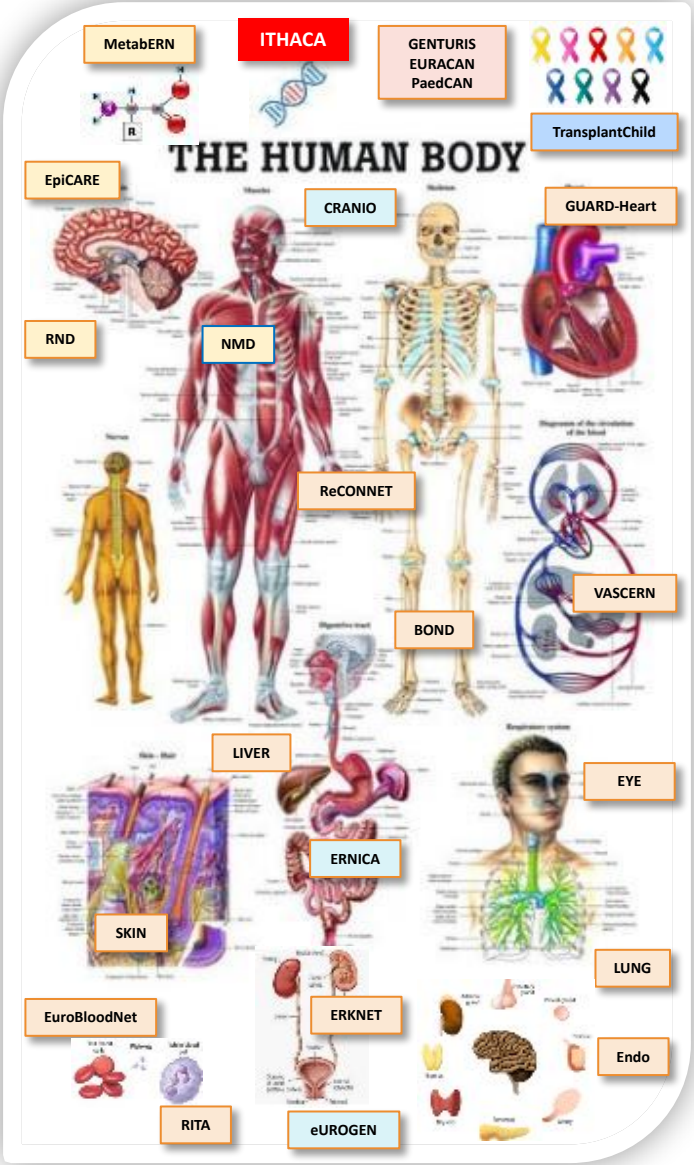
European Reference Networks

European Commission

24 ERNs covering all aspects of rare/complex human diseases + rare cancers

Organs/systems (12)

- Gateway to Uncommon And Rare Diseases of the HEART (GUARD-HEART)
- Respiratory Diseases (ERN-LUNG)
- Rare Hepatological Diseases (RARE-LIVER)
- European Rare Kidney Diseases (ERKNet)
- Rare Multisystemic Vascular Diseases (VASCERN)
- Rare Endocrine Conditions (Endo-ERN)
- Rare Bone Disorders (ERN BOND)
- Rare and Undiagnosed Skin Disorders (ERN-Skin)
- Rare Hematological Diseases (EuroBloodNet)
- ERN on Rare Eye Diseases (ERN-EYE)
- Rare Immunodeficiency, Autoinflammatory and Autoimmune Diseases Network (ERN RITA)
- Rare Connective Tissue and Musculoskeletal Diseases Network (ERN ReCONNET)



Neurology (4)

- Rare and Complex Epilepsies (EpiCARE)
- Rare Neurological Diseases (ERN-RND)
- Rare Neuromuscular Diseases (Euro-NMD)
- Rare Hereditary Metabolic Disorders (MetabERN)

Surgery/mixed (4)

- Rare craniofacial anomalies and ENT disorders (ERN CRANIO)
- Rare inherited and congenital anomalies (ERN ERNICA)
- Rare Urogenital Diseases (eUROGEN)
- Transplantation in Children (TransplantChild)

Oncology (3)

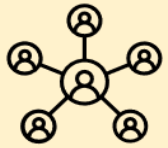
- GENetic TUmour RIsk Syndromes (ERN GENTURIS)
- Rare Adult Cancers (solid tumors) (EURACAN)
- Paediatric Cancer (haemato-oncology) (PaedCan)

Source: Presentation from ERN ITHACA

European Commission

ERNs and rare diseases

Total EU4H grants: €123.9 M



3HP ERN grants

28.3 M€

2017-2019
Yearly grants

2019-2022
Multiannual grants

2020-2023
Multiannual registries grants

24 ERNs

26.9 M€

2022- 2023
Bridging grants

2021
EUROGEN bridge
(1 grant)
0.2 M €

3HP

24 ERNs

77.4 M€

2023-2027

ERNs pool and disseminate **knowledge, expertise and resources** on **rare or low prevalence diseases** and their health professionals.

- **Clinical Patient Management System** (CPMS),
- **ERN registries,**
- Healthcare professionals **training and capacity building**,
- Clinical practice guidelines & **decision support tools.**

EU4H

JA JARDIN

15.0 M€

1 JA
Integration of ERNs into national healthcare systems

ORPHANET

4.4 M€

2 DG
Rare diseases nomenclature (ORPHAcode)

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Activities & results

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Some ERNs activities…

Training and Education

Registries

Virtual Expert Discussions

Care pathways and patients' journeys

Clinical Practice Guidelines

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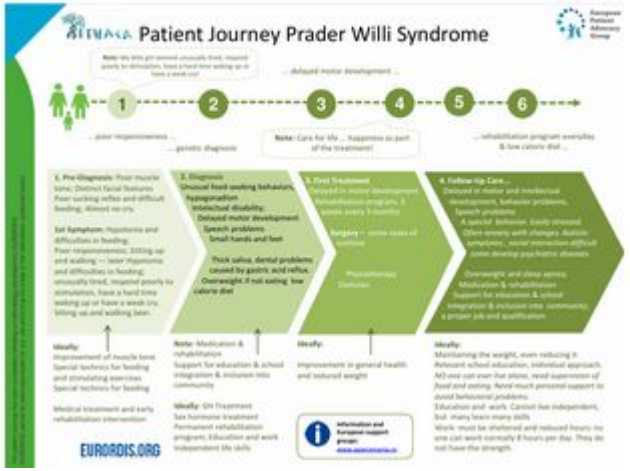
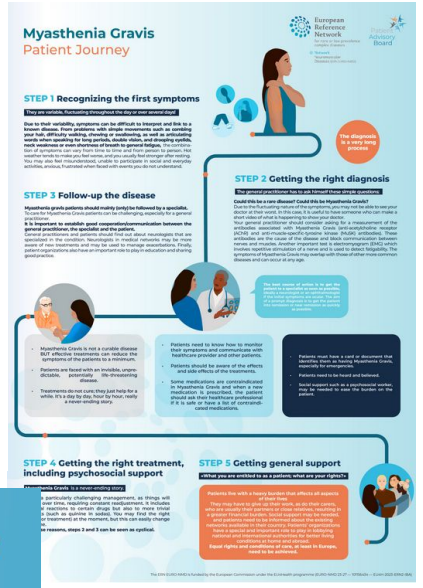
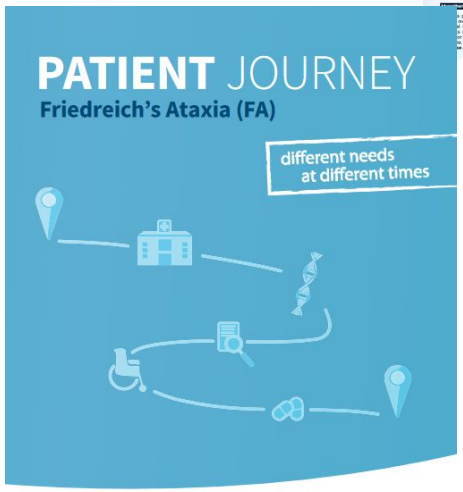
An example: Patient Journeys

- **Info-graphical overviews** that visualise patients' needs in the care of their rare disease
- **Co-produced by patients and clinicians**
- Represent a step forward toward systematic patient engagement in the design of care pathways







European Reference Network for rare or low prevalence complex diseases
Network Neurological Diseases (ERN-RND)

Friedreich's Ataxia Research Alliance IRELAND

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An example: Virtual Expert Discussions through the CPMS

The **Clinical Patient Management System (CPMS)** is a **virtual platform** that allows healthcare professionals from different countries to work together on complex cases, sharing expertise and knowledge.

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JARDIN Joint Action

- **Duration:** January 2024 – January 2027. **Budget:** 18.8 M€ (of which 15.0 M € EU contribution)

- **Aim:** achieve the integration of European Reference Networks (ERNs) into National Healthcare Systems.

- **Expected results**: recommendations, guidelines, and toolboxes suited for the needs of all Member States, as well as support of capacity building and performing implementation pilots in areas such as patient pathways and data management.

European Commission

Thank you

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