Feedback to policy: harvesting the results of EU-funded projects on public health

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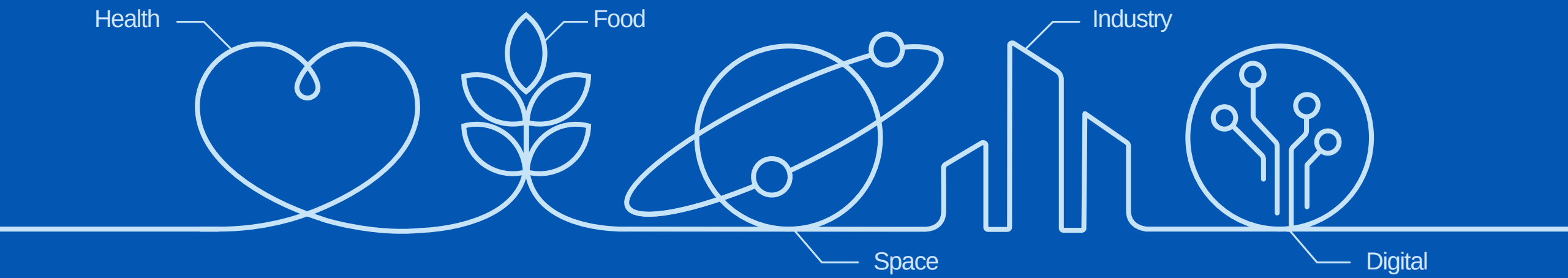
ProMIS Summer School 2025
Genoa, 3 July 2025

A quick overview on who we are and what we do

European Commission

HaDEA: Delivering results through implementation

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, food, digital, industry and space.



European Commission vs Executive Agencies

European Commission

Directorates-General (DG SANTE, DG CONNECT, etc…)

- Definition of policies
- Drafting of Work Programmes

Executive Agencies

(HaDEA, CINEA, REA, etc…)

- Implementation of calls for proposals/ procurement procedures
- Management of funded projects

HaDEA is working closely with 6 Directorates-General of the European Commission

SANTE
Health & Food Safety

RTD
Research & Innovation

GROW
Internal Market, Industry, Entrepreneurship and SMEs

DEFIS
Defence Industry & Space

HERA
European Health Emergency Preparedness and Response Authority

CNECT
Communications Networks, Content & Technology

The programmes we manage

Health

EU4Health

-

Horizon Europe – Health Research

Food

Single Market Programme (SMP): Food Safety

Digital

Horizon Europe – Digital

-

Connecting Europe Facility – Digital

-

Digital Europe Programme

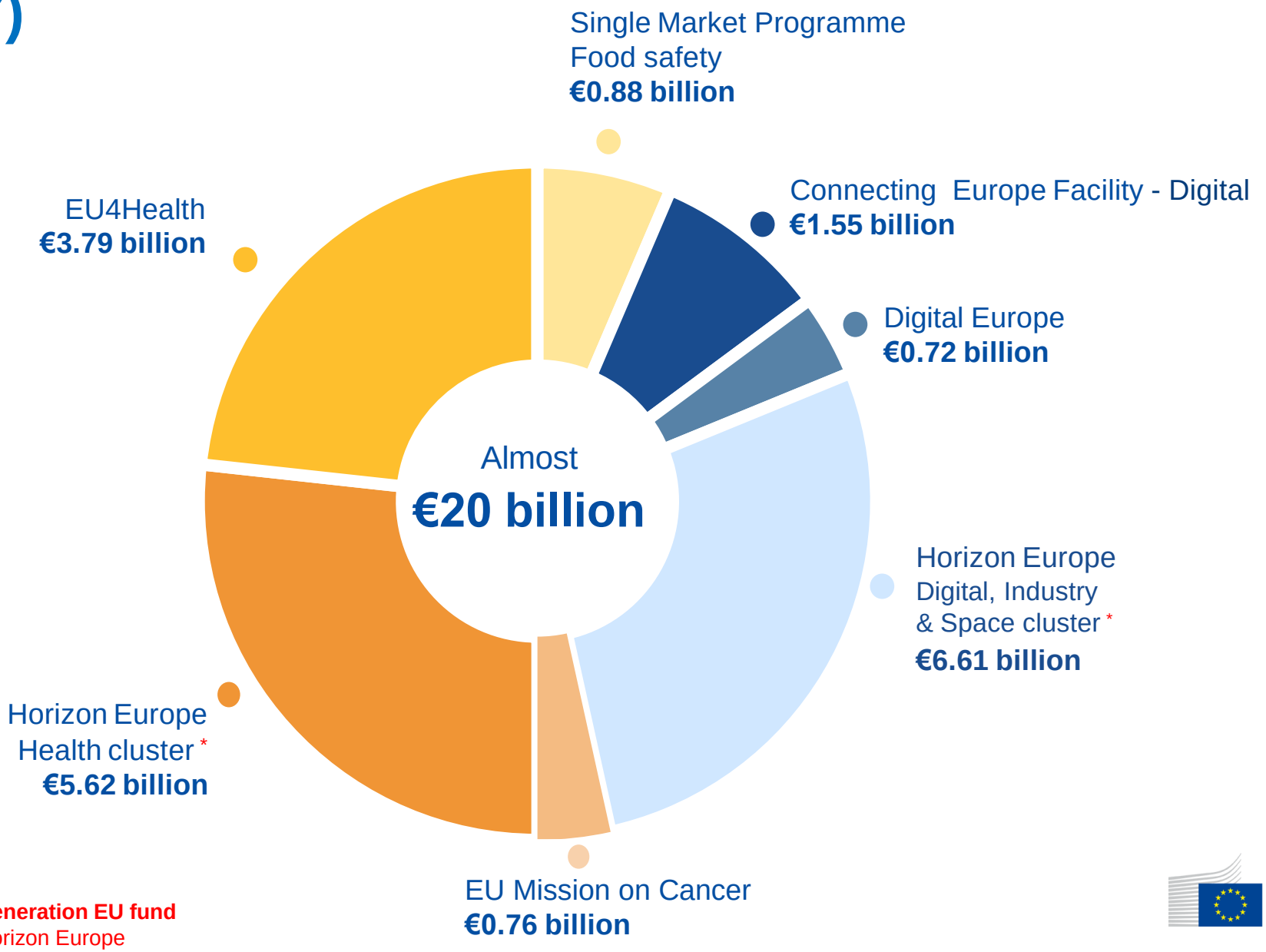
Industry

Horizon Europe – Industry

Space

Horizon Europe – Space

Budget managed by HaDEA (2021-2027)



*The budget includes a portion of the **Next Generation EU fund** supporting the health and digital strands of Horizon Europe

European Commission

Zooming into two EU funding programmes devoted to public health

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The most ambitious EU Research and Innovation funding programme

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Horizon Europe Cluster 1 ‘Health’
(Multi-Annual Work Programmes)

1. Staying healthy in a rapidly changing society
2. Living and working in a health-promoting environment
3. Tackling diseases and reducing disease burden
4. Ensuring access to innovative, sustainable and high-quality health care
5. Unlocking the full potential of new tools, technologies and digital solutions for a healthy society
6. Maintaining an innovative, sustainable and globally competitive health industry

EU4Health

EU4Health represents an unprecedented level of financial commitment to improve and foster health in Europe

European Commission

EU4Health: 5 thematic strands, with cancer as cross-cutting theme

Strands of action

CANCER

- CRISIS PREPAREDNESS
- HEALTH PROMOTION & DISEASE PREVENTION
- HEALTH SYSTEMS & HEALTHCARE WORKFORCE
- DIGITAL TRANSFORMATION

European Commission

Feedback to Policy

European Commission

Feedback to Policy: a delegated task

EUROPEAN
COMMISSION

Brussels, 12.2.2021
C(2021) 948 final

COMMISSION DECISION

of 12.2.2021

delegating powers to the European Health and Digital Executive Agency with a view to the performance of tasks linked to the implementation of Union programmes in the field of EU4Health, Single Market, Research and Innovation, Digital Europe, Connecting Europe Facility – Digital, comprising, in particular, implementation of appropriations entered in the general budget of the Union

(Only the English text is authentic)

To provide feedback to the Commission to serve as input for monitoring, reviewing and rectifying existing policy measures or shaping new policy initiatives and decisions, the Agency shall identify and report on the relevant knowledge acquired from the management of the programmes and their results. The specific arrangements and content of that feedback to policy activities shall be set out in the Memorandum of Understanding.

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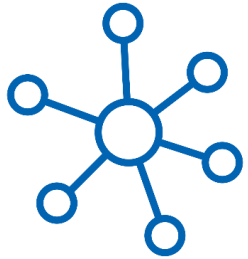
Feedback to policy plans: in practice

Policy needs by parent DGs

Policy objectives and priorities, strategic planning and programme development



Knowledge sharing and communication

Policy monitoring and evaluation

Legislation and regulation and its implementation

Input by HaDEA

Analysis and support

Reports and communication

Meetings and events

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Feedback to policy through synergies

Synergies by design

- Foreseen at programming level (i.e. directly specified in the call text)

Synergies by implementation

- Promoted by the Agency to support a coherent project portfolio

WITHIN

Between

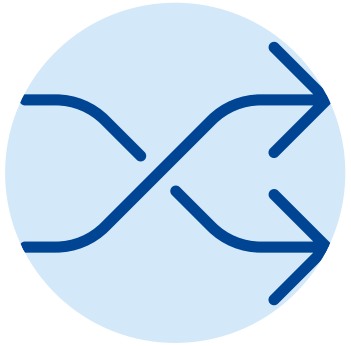
European Commission

How do synergies unfold?

Complementary funding: bringing together funding from different programmes or different levels in the same project

Sequential funding: successive projects that build on each other

Alternative funding: taking up high-quality project proposals from other programmes (e.g. SoE)



Complementarity of parallel **projects**

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Digital Health: A clear example of synergies

Horizon Europe Cluster 1

Total number of grants: 158
EU contribution: 1.9 billion EUR

Horizon Europe Cluster 4

Total number of grants: 18
EU contribution: 91.7 MIL EUR

EU4Health
Focus on primary and secondary uses of health data

Total number of grants: 68
EU contribution: 105.2 MIL EUR

Total number of procurements on eHealth Data Space: 9
Total budget: 15.3 MIL EUR

Digital Europe Programme
Three Specific Objectives addressing Digital Health

Total number of grants: 5
EU contribution: 26.5 MIL EUR

CEF- Digital
5G for healthcare applications in hospitals

Total number of grants: 14
EU contribution: 42.5 MIL EUR

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HaDEA's Project Showcase Events

Synergies to foster a comprehensive approach to Mental Health

Synergies to beat Cancer

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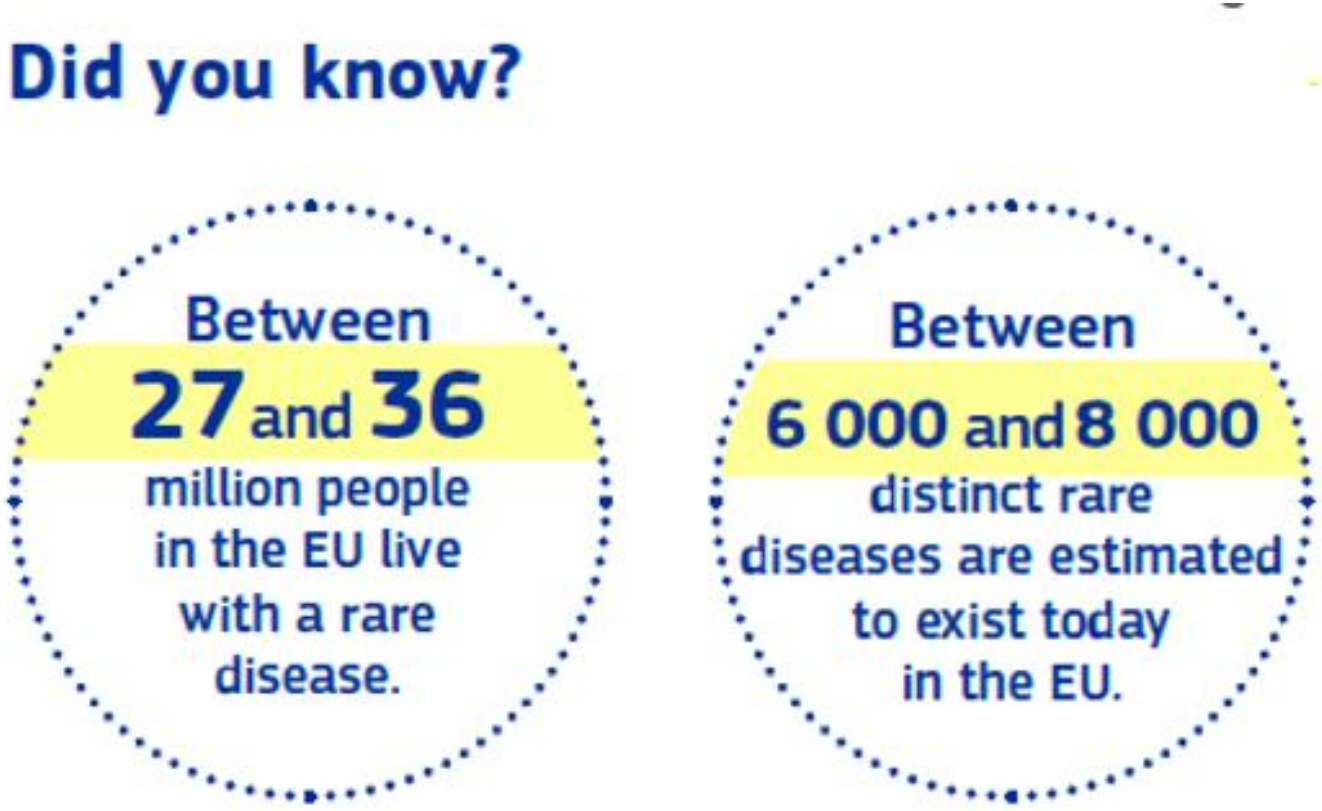
A tangible example of Feedback to Policy: The European Reference Networks (ERNs)

Marika Mazzei
Project Officer, Unit A1 EU4Health

Rare Diseases



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

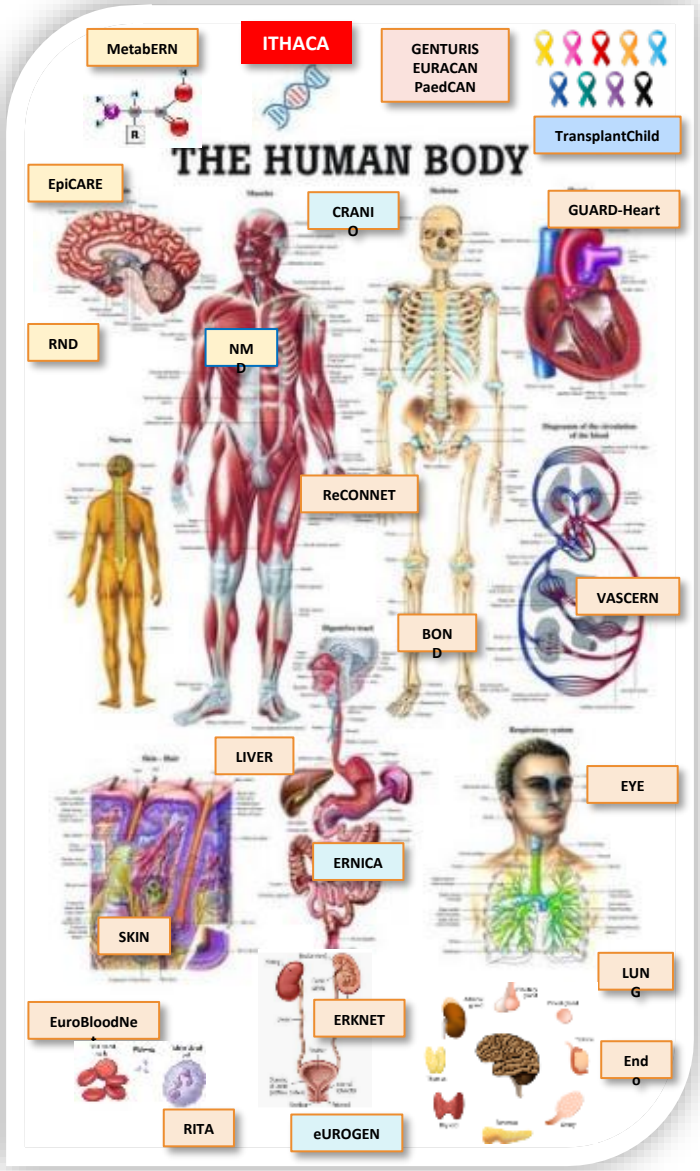
European Reference Networks

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

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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: 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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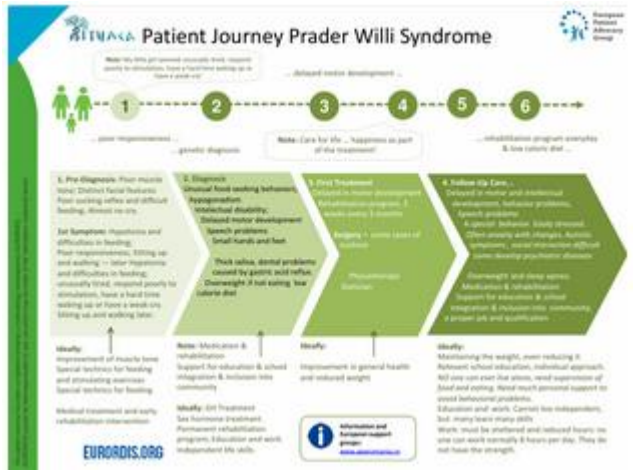
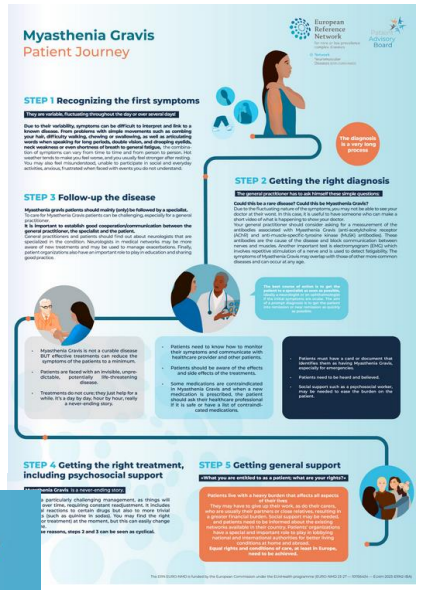
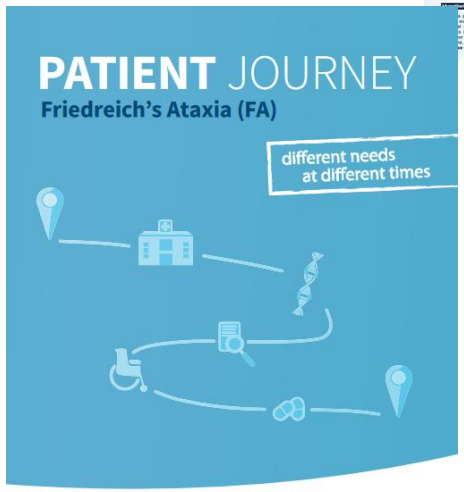
An example: Patient Journeys

- **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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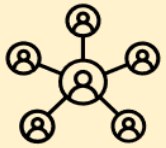
ERNs and rare diseases

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

3HP

24 ERNs

26.9 M€

2022- 2023
Bridging grants

2021
EUROGEN bridge
(1 grant)
0.2 M €

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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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.

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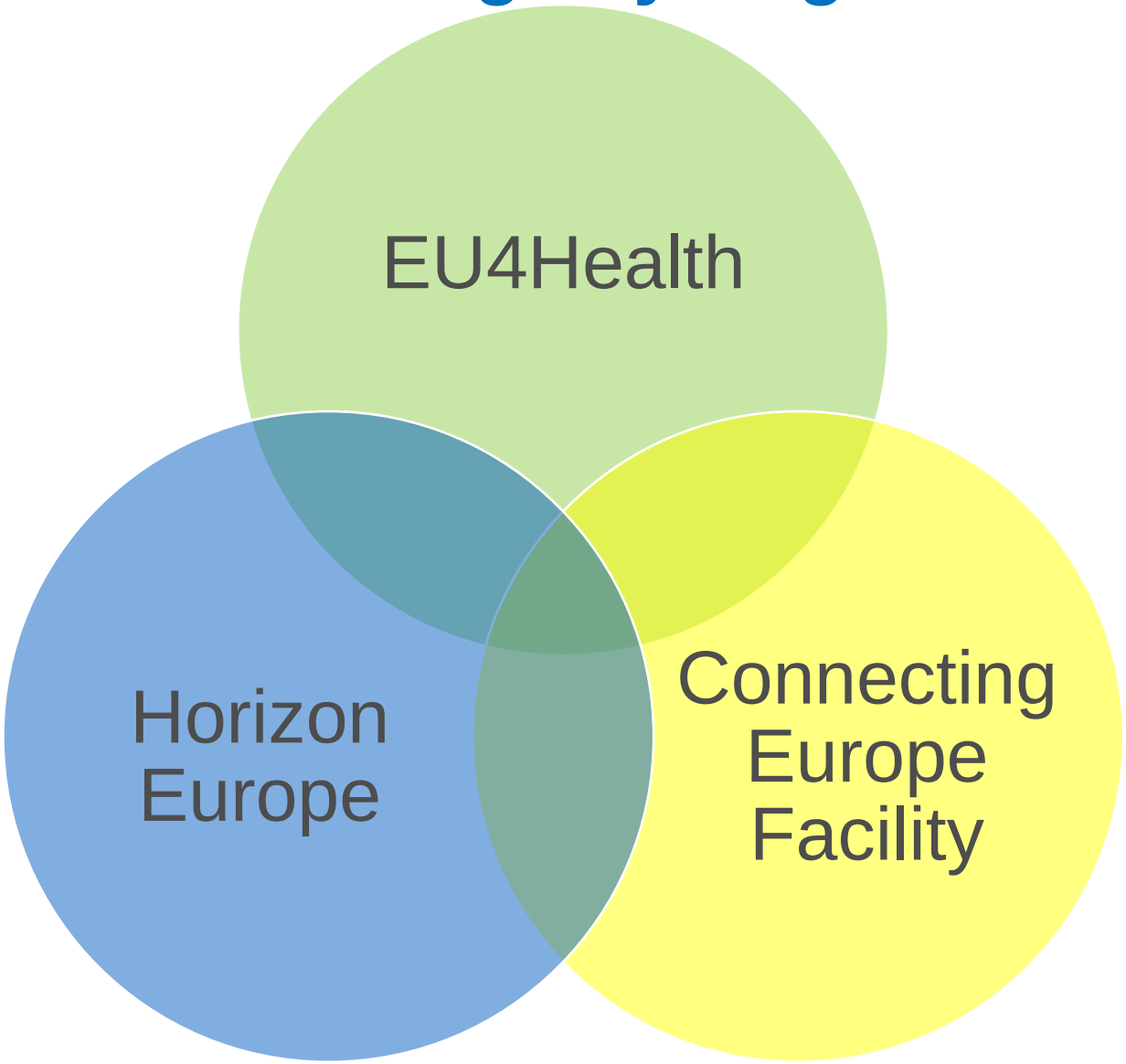
Tackling rare and complex diseases through synergies



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Thank you & Stay in touch

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