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SNOMED CT EXPO 2017
Bratislava, 19 October 2017

#ERNEU
@EU_Health

European Reference Networks

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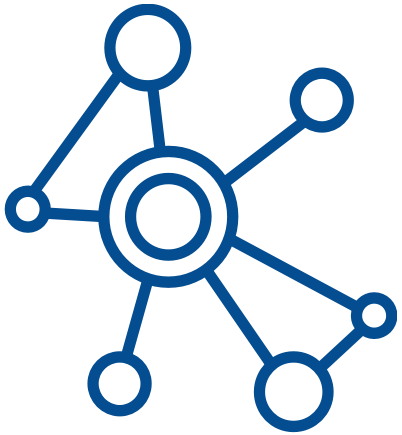
"The knowledge travels, not the patient"

- **Treat and diagnose patients:** exchange clinical **data on patient cases** at a distance
- **Develop and exchange expertise** through the network and across the EU
- **Networking, research and training**
- **Patient management software for virtual care**



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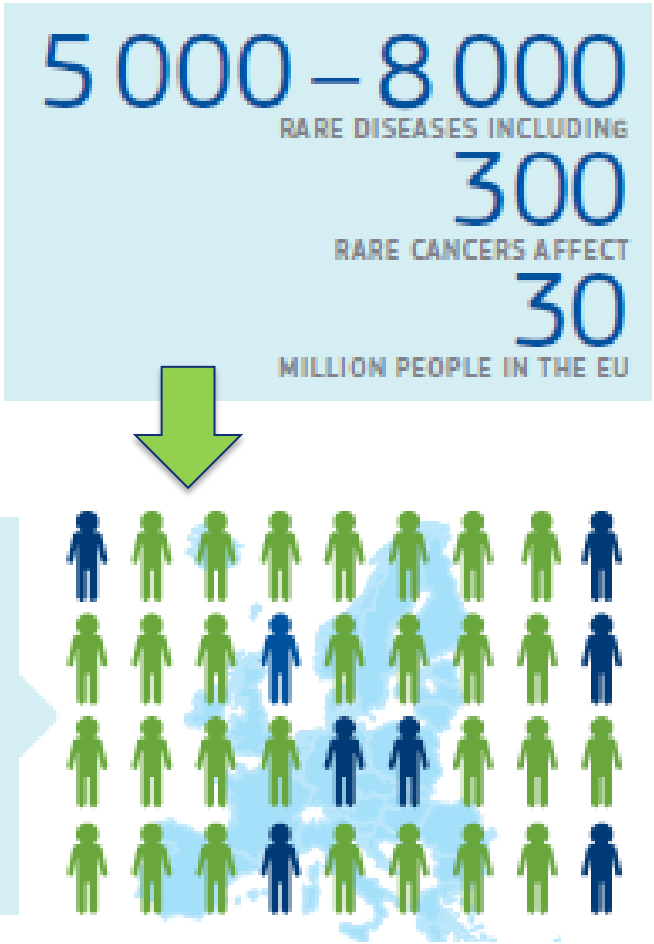
The Rationale



- Many affected by a rare or complex condition do not have access to diagnosis and high-quality treatment.
- Expertise and specialist knowledge may be scarce because patient numbers are low
- No country alone has the knowledge and capacity to treat all rare and complex diseases.
- Important delay in diagnosis because lack of knowledge or right referral systems
- Lack of diagnostic capacity (tests) and treatments in many cases

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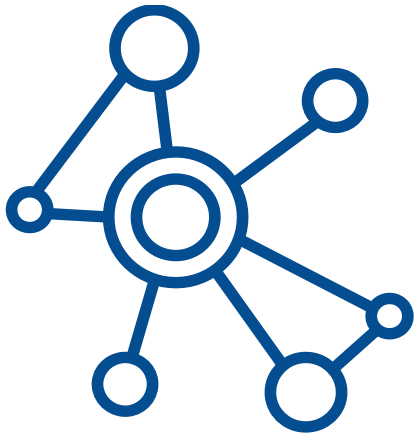

Networks

26 COUNTRIES

› 300 HOSPITALS

Full Member

› 900 HEALTHCARE UNITS

Health

AWARD CEREMONY

3rd European Reference Networks Conference

9 March 2017 - Vilnius, Lithuania

BOND ERN	Bone Diseases	**EuroBloodNet**	Onco-Hematological Diseases
CRANIO	Craniofacial anomalies and ENT disorders	**EUROGEN**	Urogenital Diseases
Endo-ERN	Endocrine Conditions	**EURO-NMD**	Neuromuscular Diseases
EpiCARE	Rare and Complex Epilepsies	**GUARD-HEART**	Diseases of the Heart
ERKNet	Kidney Diseases	**ITHACA**	Congenital Malformations and Intellectual Disability
ERN GENTURIS	Genetic Tumour Risk Syndromes	**MetabERN**	Hereditary metabolic diseases
ERN-EYE	Eye Diseases	**RARE-LIVER**	Hepatological Diseases
ERNICA	inherited and congenital anomalies	**ReCONNET**	Connective Tissue and Musculoskeletal Diseases
ERN-LUNG	Respiratory Diseases	**RITA**	Immunodeficiency, AutoInflammatory and Auto Immune Diseases
ERN-RND	Neurological Diseases	**TRANSPLANT-CHILD**	Transplantation in Children
ERN-Skin	Skin Disorders	**VASCERN**	Multisystemic Vascular Diseases
ERN Paedcan **EURACAN**	Rare Paediatric Cancers Solid Adult Cancers		

Share. Care. Cure.

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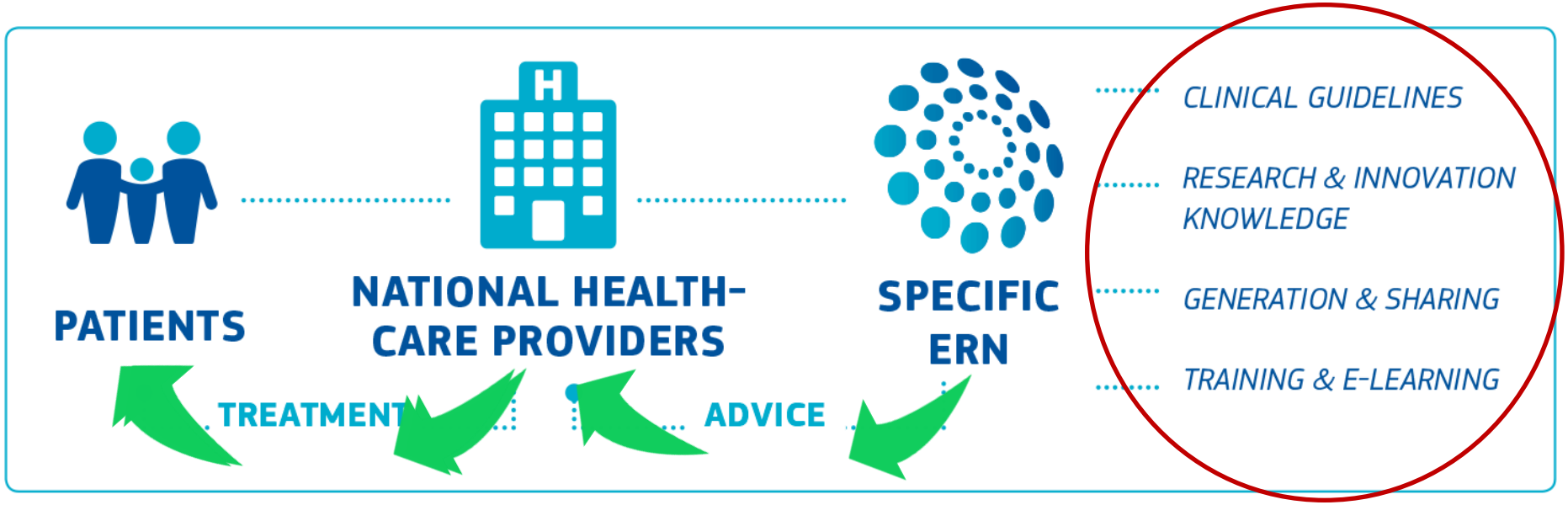

Virtual clinical care

Research

Knowledge generation

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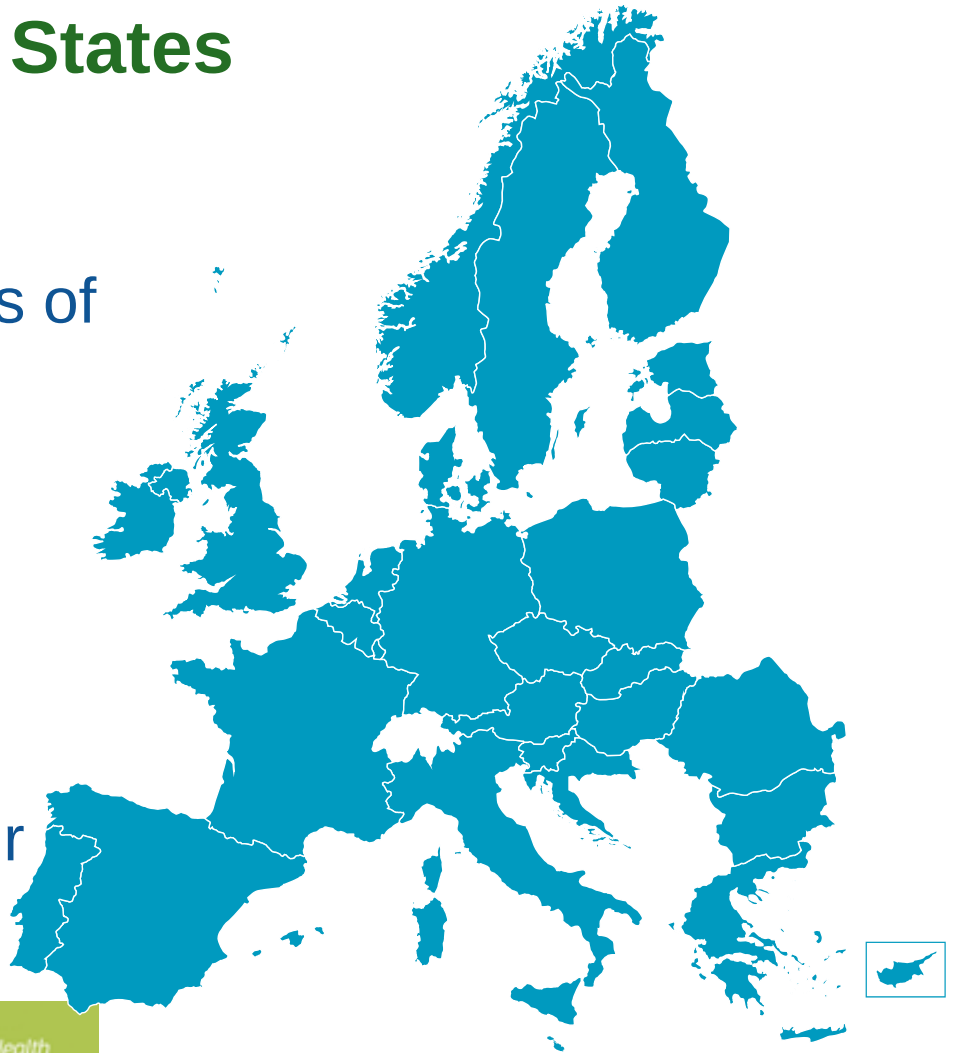
Key role of the Member States

Member States

- Recognise HCPs or centres of expertise at national level
- Endorse applications

Board of Member States

- Develop strategy
- Approve Networks and their members



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Challenges for the near future

- Integration of ERNs into the National Healthcare systems
- Referral systems and patient pathways at national level
- Support of the ERN clinics and ERN networks
- Sustainability

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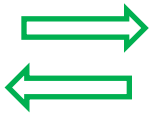
Actors



BoMS

ERNs' Coordinators

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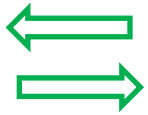

National Healthcare System

Commission expert group on rare diseases

RD ACTION DATA AND POLICIES FOR RARE DISEASES

JARC JOINT ACTION ON RARE CANCERS

Patients organisations

Professional / scientific organisations

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DG SANTE

DG CONNECT
DG RTD
JRC

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European Reference Network & its IT Platform

1) ERN Collaborative Platform
2) ERN Clinical Patient Management System
3) ERN Public Website

Clinical Patient Management System

- Building the ERN Clinical Patient Management System is a huge challenge.
- No such multi-country clinical system exists yet.
- We can expect many organisational, semantic and technical challenges.

Clinical Patient Management System

Software as a Service – key parameters

- *Planned delivery of the first version in 2017*
- *Proven, working, existing software*
- *Sharing of clinical data, including medical imagery*
- *All the ERNs use the same system*

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Clinical Patient Management System

1. Register the patient enrolled into an ERN consultation

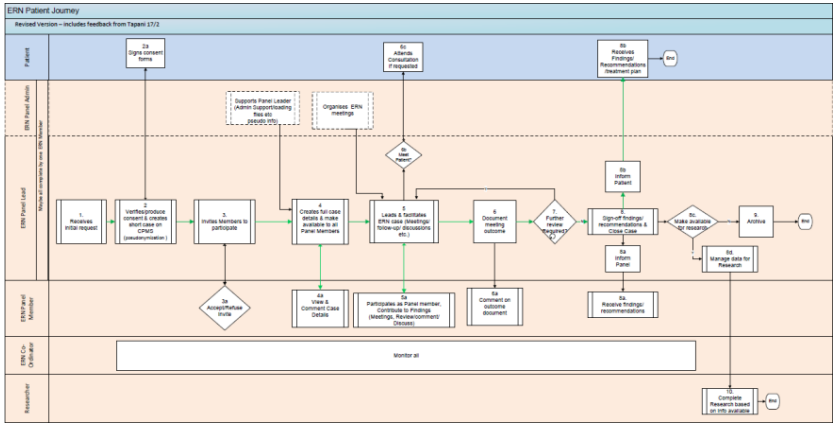
   Confirm and record the patients' consent

2. Share clinical, pseudonymised data on the patient

- Consultation process to arrive at clinical conclusions on diagnosis and treatment

3. Archive the patient case data, forming the ERN patient register

   Optionally transfer data to research projects



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Registries under the Health Programme 2017

- **ERK-REG** - ERKNet Registry for Rare Kidney Diseases
- **EuRRECa** - European Registries For Rare Endocrine Conditions
- **PARTNER** - ERN-PAEDCAN Partner: Paediatric Rare Tumours Network - European Registry
- **Registry Warehouse** - RD Registry Data Warehouse
- **U-IMD** - Unified European Registry for Inherited Metabolic Disorders

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ERN IT Platform

- ❑ Registration of patient data for care / treatment purposes
- ❑ Virtual consultations
- ✓ Creation of new registries
- ✓ Interoperability of existing registries

EU RD Platform

- ✓ Interoperability for the 600+ European registries, including ERN registries
- ✓ Support for creation of new registries
- ✓ Standards and tools for RD registries

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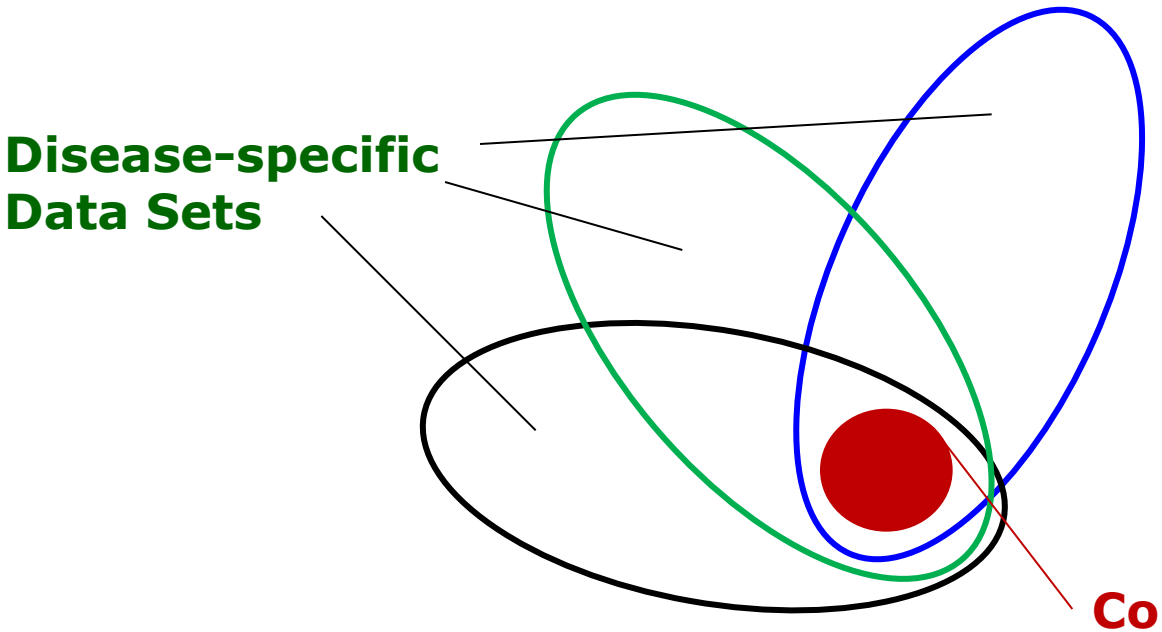
Data sets



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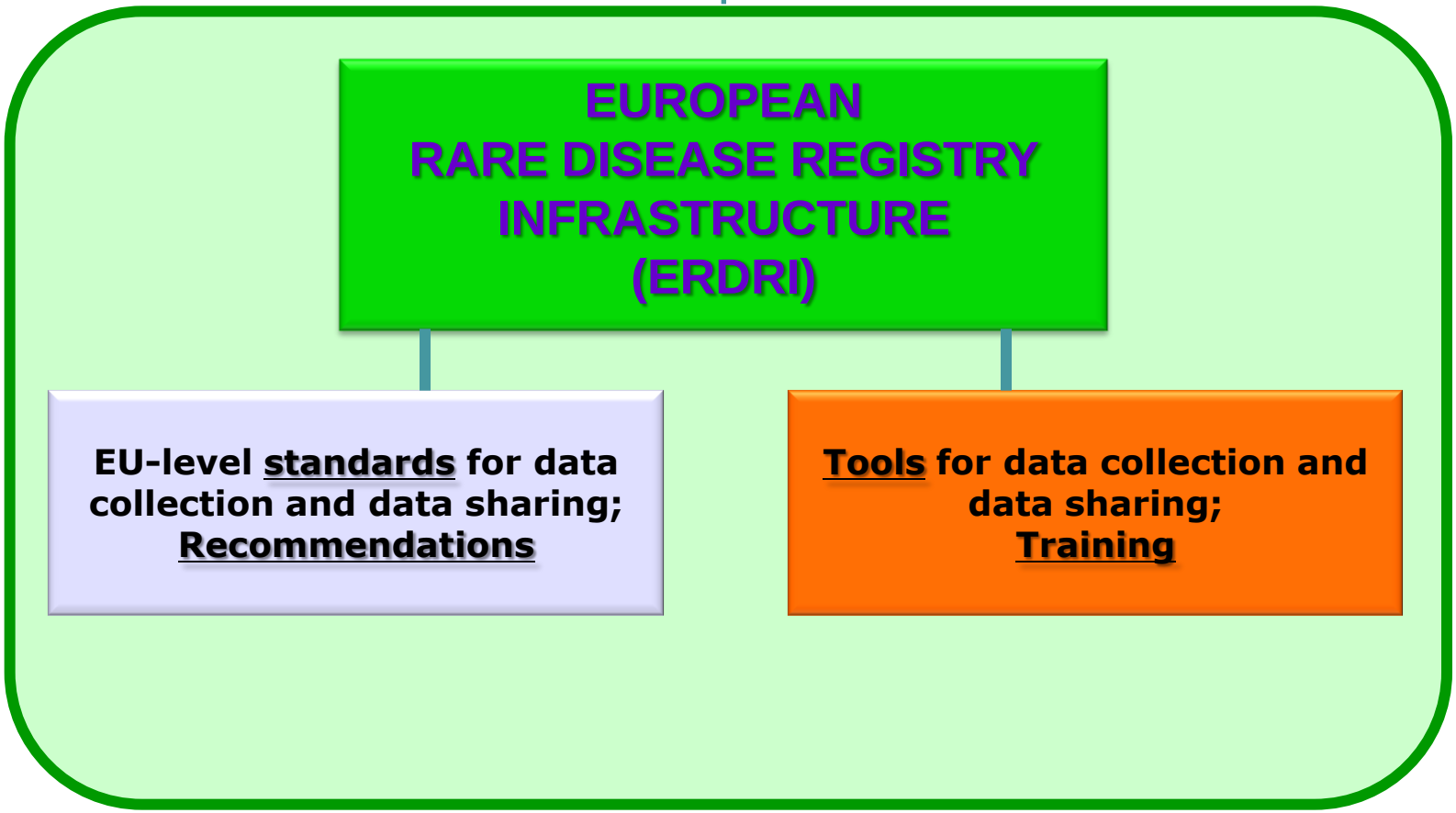
EU RD Platform



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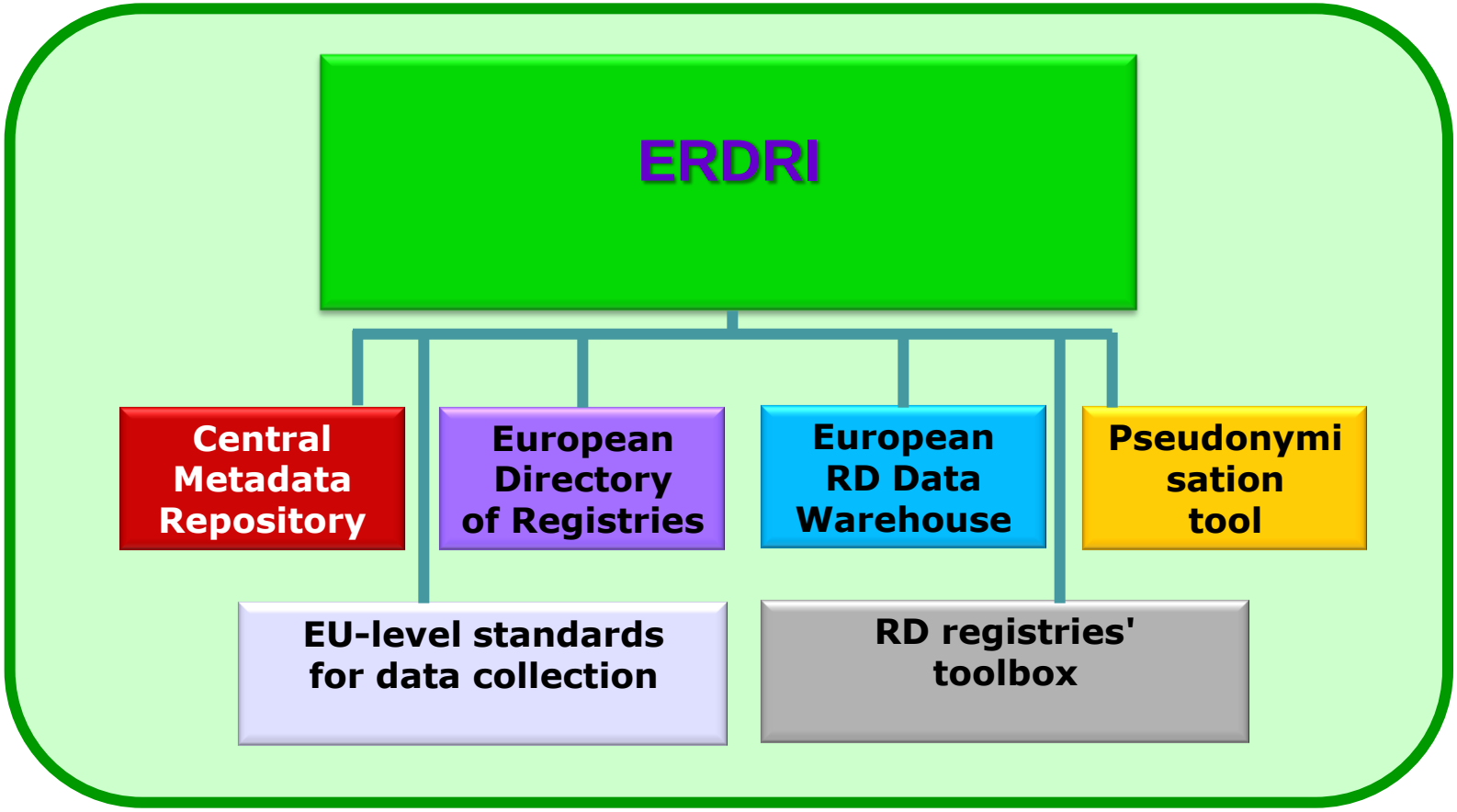
EU RD Platform



Development and Maintenance of the European Platform on Rare Diseases Registration

Directorate-General
Joint Research Centre
(DG JRC – F.1.)

Directorate-General
Health and Food Safety
(DG SANTE – C.1.)

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Expected impact of the ERNs for patients and professionals

- ✓ improve public and professional awareness of rare and complex diseases
- ✓ increase the likelihood of early and accurate diagnosis and effective treatment where available.
- ✓ platforms for the development of guidelines, training and knowledge-sharing.
- ✓ facilitate large clinical studies to improve understanding and develop new drugs
- ✓ An opportunity for networking with likeminded experts from across Europe — ending the professional isolation that many experts in rare diseases face.

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Expected impact of the ERNs for the Healthcare systems and society

- ✓ Innovation in healthcare delivery is the cornerstone of the ERN system
- ✓ Incubators for the development of digital services for the provision of virtual healthcare.
- ✓ Development of new care models, and innovative medical solutions and devices, changing the way in which treatment itself is delivered.
- ✓ Will help to boost economies of scale and ensure a more efficient use of resources, with a positive impact on the sustainability of national healthcare systems.

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DG Health and Food Safety site

https://**ec.europa.eu/health/ern/policy_en**

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Working for patients
with rare, low-prevalence
and complex diseases
Share.Care.Cure.