ERN BOND Coordinator
Dr. Luca Sangiorgi
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'Registries and ERNs'

EuRREB
European Registries for Rare
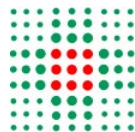Endocrine and Bone conditions

Registries and ERNs

Dr. Luca SANGIORGI – ERN BOND Coordinator

IRCCS Istituto Ortopedico Rizzoli

EuRREB
European Registries for Rare
Endocrine and Bone conditions

SERVIZIO SANITARIO REGIONALE
EMILIA - ROMAGNA
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ERNs – European Reference Networks

ERNs are **cross-border networks** that **bring together European hospital centres of expertise** to tackle rare, low prevalence and complex conditions requiring highly specialized healthcare

The 24 **ERNs were launched in March 2017** and they now **include 1,613** specialized centers located in 382 hospitals across 27 Member States and Norway
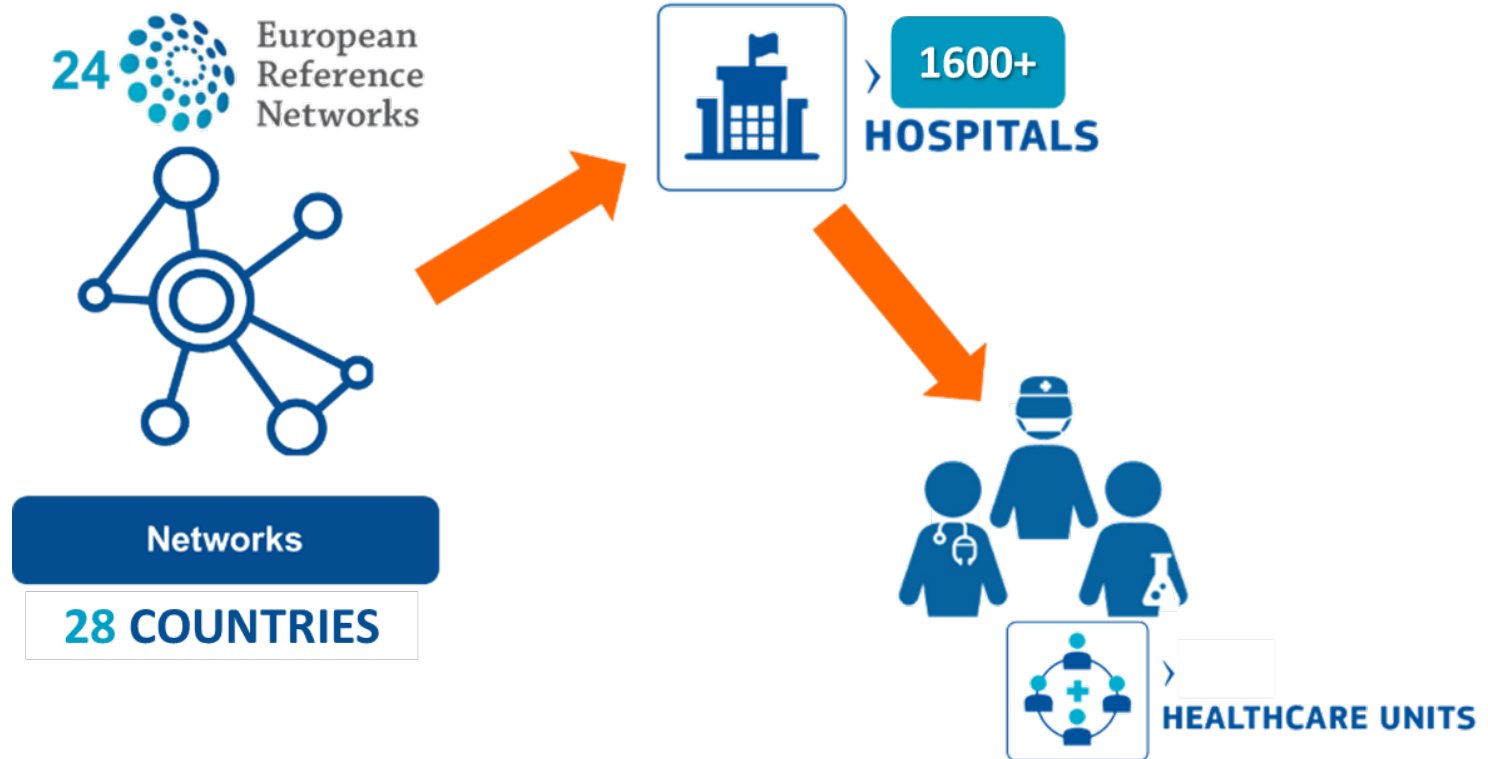
ERNs: 24 thematic networks
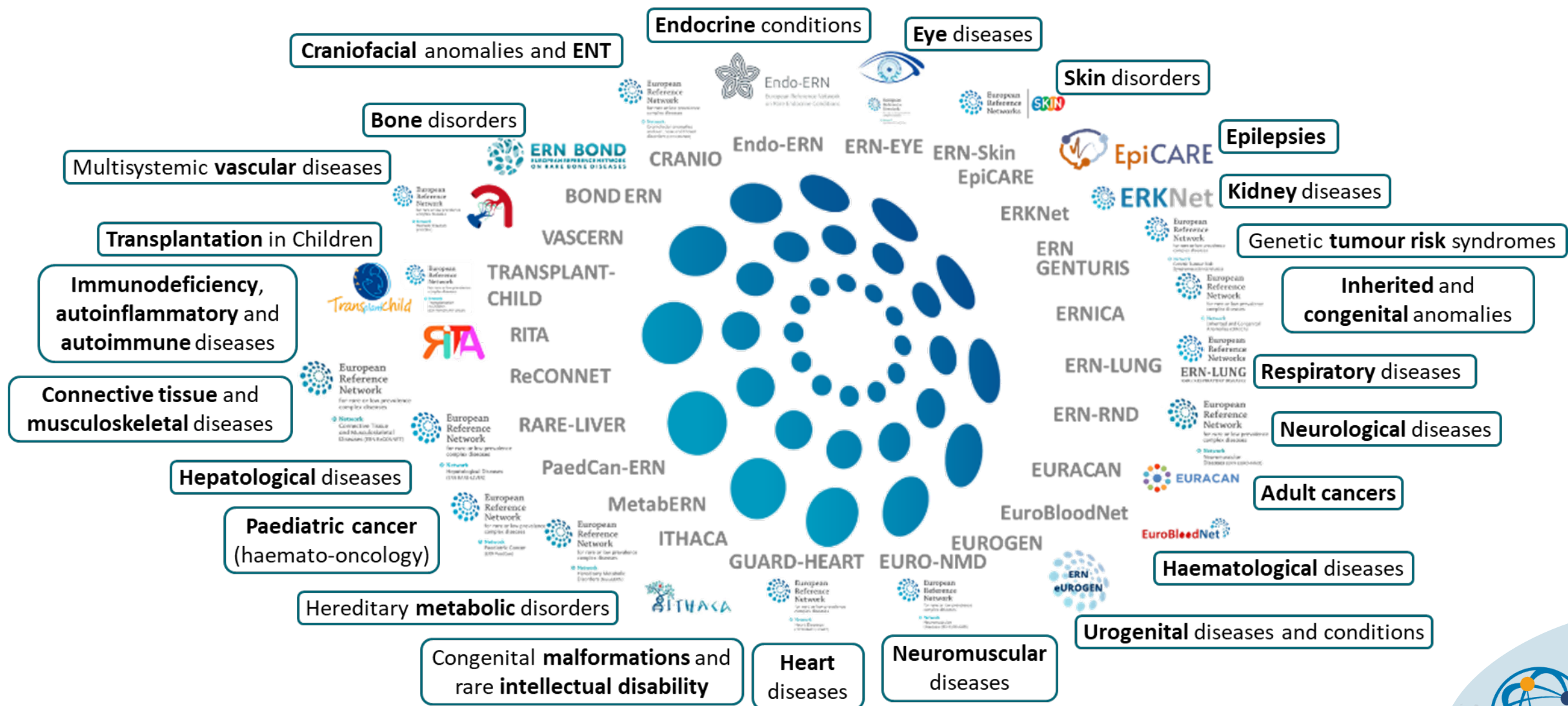
ERNs and Registries

In the past years, all ERNs have created their Patient registry

- **ERN BOND** & **ENDO ERN** - EuRREB registries - https://eurreb.eu

- ERN CRANIO - ERN CRANIO registry - https://erncranio.molgenis.net/CranioPublic/cranio-public/#/

- ERN EpiCARE - REDCap EpiCARE registry - https://epi-care.eu/epicares-activities/registry-project/

- ERKNet - ERKReg - https://www.erknet.org/patients-registry/registry-mission

- ERN-RND - ERN-RND Registry - https://www.ern-rnd.eu/ern-rnd-registry/?cn-reloaded=1#registry-objectives

- ERNICA - EPSA|ERNICA registry - https://www.ernernica.eu/registry

- ERN-LUNG - BREATHeREGISTRY - https://ern-lung.eu/patient-registry/breatheregistry/

- ERN-Skin - ERN-Skin registry - https://ern-skin.eu/erras-registry/

- ERN EURACAN - EURACAN Registry - https://registry.euracan.eu/

- ERN EuroBloodNet - ENROL registry - https://enrolnetwork.eu/

- ERN eUROGEN - ERN eUROGEN registry - https://eurogen-ern.eu/our-work/registry/

- ERN EURO-NMD - EURO-NMD Registry - https://ern-euro-nmd.eu/reghub/

ERNs and Registries

- ERN EYE - REDgistry - https://redgistry.eu/

- ERN GENTURIS - ERN GENTURIS Registry - https://genturis-registry.eu/menu/main/app-ern-genturis/

- ERN GUARD-Heart - Heart-Core registry - https://guardheart.ern-net.eu/disease-registries/heart-core-registry/

- ERN-ITHACA – ILIAD - https://ern-ithaca.eu/our-research-activities/iliad/

- MetabERN - U-IMD Registry - https://www.u-imd-registry.org/index.php?id=about

- ERN PaedCan - PARTNER registry - https://partner.datariverweb.com/myhealthtest/

- ERN RARE-LIVER - R-LIVER Registry - https://rare-liver.eu/patients/r-liver-registry/

- ERN ReCONNET - TogetherERN ReCONNET Registry Platform - https://reconnet.ern-net.eu/our-activities-registry/

- ERN RITA - RITA Registry - https://ern-rita.org/rita-registry/general-info/

- ERN TRANSPLANT-CHILD - PETER registry - https://peter.transplantchild.eu/

- VASCERN - VASCERN registry - https://vascern.eu/group/registry/

ERN Coordinators Group

The **ERN Coordinators Group** is the main governance body of the ERNs and is composed by the 24 Coordinators. This group serves as a platform to discuss and coordinate technical, organizational, and strategic aspects of the ERNs' work

ERN Coordinators Group Meeting in Rome, May 2025

This Group has settled several working groups on specific topic.

The **Registries Working Group**, lead by Franz Schaefer, is intended to oversee the development and implementation of patient registries within the ERN framework, continuing the work of ERICA project

ERN Registries

Each ERN has developed a Registry with the shared **general purpose of collecting data from rare patients**

Despite this, they have been conceived, designed and realized following very different approaches in terms of:

- ✓ Access
- ✓ Structure
- ✓ Governance
- ✓ IT platform
- ✓ …

FEW GENERAL EXAMPLES OF THE DIFFERENT APPROACHES

- Different **target disease**: some registries have been designed for a specific disease/condition or, at least a small group of conditions, while other collect all the ERN patients' data

- Different **platforms**: some ERNs preferred to implement the registry on REDCap, while other selected a dedicated platform

- Different **data type**: most registries clearly stated the implementation of JRC Set of Common Data Elements, while other didn't. Moreover, the type of data collected are very dissimilar (i.e. including or not the genetic background)

ERN Registries Approaches 2/2

**FEW GENERAL EXAMPLES OF THE DIFFERENT APPROACHES**

- Different **structure**: unique registry for all the patients, a registry for each disease, patients grouped by diagnosis (clinical, molecular, undiagnosed), comprising common data and "sub-registries" for specific conditions, etc.

- Different **access**: some registries allow both experts and patients access (i.e. PROs), while other are intended only for experts

- Different **locations**: some registries (of the same ERN) are hosted together, while other are located on multiple sites (i.e. depending on disease)

- Different **configuration**: centralized, federated or mixed

Centralized or federated data?

Registries data can be centralized [all information are consolidated in one place]. This approach offers an easier management and consistency, raising privacy and single-point-of-failure risks.

Registries data can be federated [information are kept distributed]. This allows local control and better privacy but adding complexity and potential data inconsistencies.

a) Centralized   b) Federated
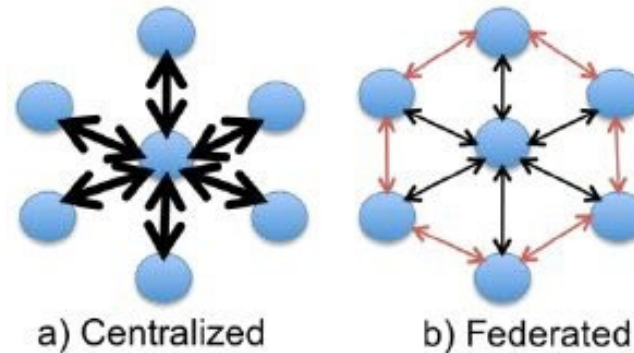
The key difference lies in data location and access: centralized data is stored and managed centrally,

while federated data remains at its source, accessed through a virtual layer for analysis

Centralized or federated data?

A synthetic overview of the characteristics of centralized and federated data

Feature	Centralized Data	Federated Data
Data Location	Single, central repository	Distributed across multiple local sources
Data Management	Central team manages all data	Local teams manage their data, with a central team for global rules
Data Access	Users access the central repository	Data is accessed via a virtual layer without being physically moved
Control	Strong central control	Local control over data
Complexity	Simpler structure, complex security if breached	More complex to coordinate, but handles privacy well

Conclusions

Thank you

Ways to contact us:

🌐 **eurreb.eu**

✉️ **registries@lumc.nl**

🖥️ **drop-in sessions via Zoom**

in **European Registries for Rare Endocrine and Bone Conditions**

EuRREB
European Registries for Rare
Endocrine and Bone conditions

Endo-ERN
European Reference Network
on Rare Endocrine Conditions

ERN BOND
EUROPEAN REFERENCE NETWORK
ON RARE BONE DISEASES