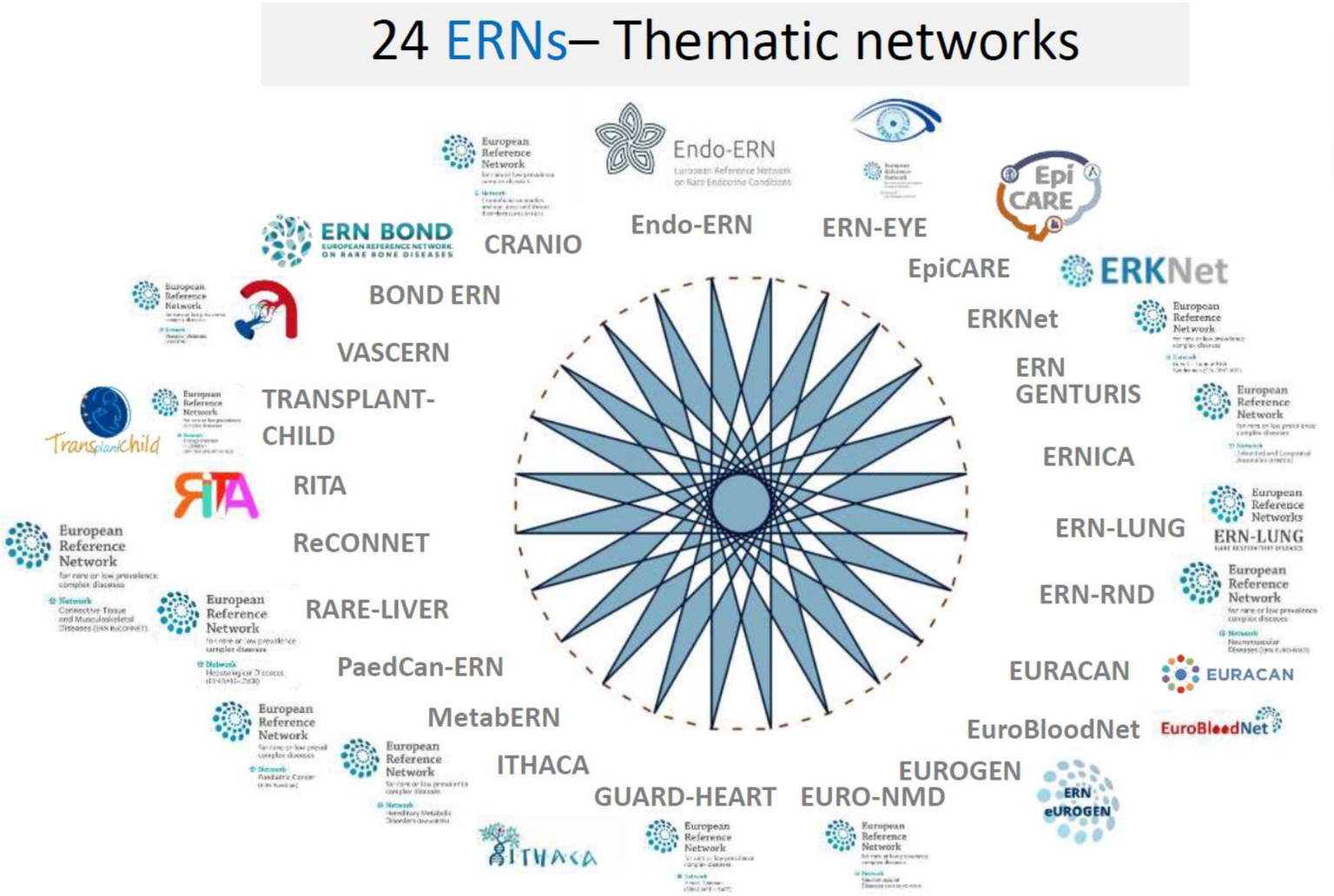
European Reference Networks

European Reference Networks

- Operational since 2017
- As of 2024, the ERNS include 1,619 specialised centres in 382 hospitals across 27 Member States and Norway.
- Focus on healthcare
- Created under Directive 2011/24/EU on patients' rights in cross-border healthcare.



European Reference Networks created added value

- European partnership
- Structural integration of patient organisations
- Knowledge and standards: Collect, make available
- Produce new knowledge, standards and data
- Increase equity of care
- E-health for cross-border care (“knowledge travels, not the patient“)

24 ERNs have been established in 2017

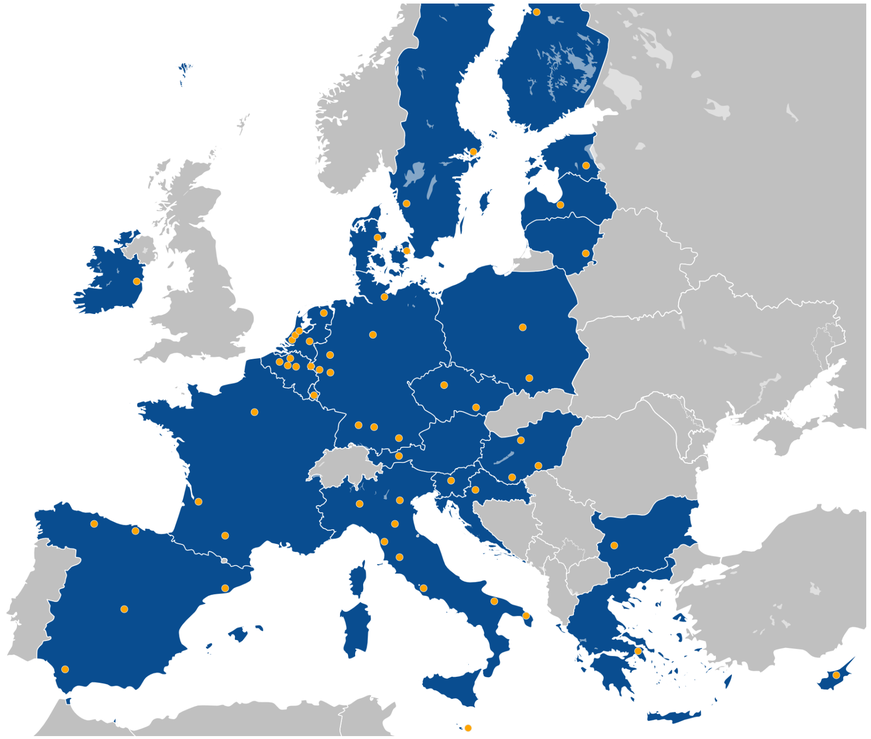
- ERN Bond
- ERN Cranio
- Endo-ERN
- ERN EpiCARE
- ERKNet
- ERN-RND
- ERNICA
- ERN Lung
- ERN Skin
- ERN EURACAN
- ERN EuroBloodNet
- ERN eUROGEN
- ERN Euro-NMD
- ERN Eye
- ERN Genturis
- ERN Guard-Heart
- ERN ITHACA
- MetabERN
- ERN PaedCan
- ERN Rare-Liver
- ERN ReCONNET
- ERN RITA
- ERN Transplant-Child
- VASCERN

ERN-RND –
European Reference Network for rare neurological diseases

- 68 expert centres in 24 EU countries (medium large ERN)

  + supporting partners

- > 44.000 patients per year (adults and paediatric)



Country	N members
Austria	1
Belgium	4
Bulgaria	1
Croatia	1
Cyprus	1
Czech Republic	4
Denmark	2
Finland	1
France	6
Germany	9

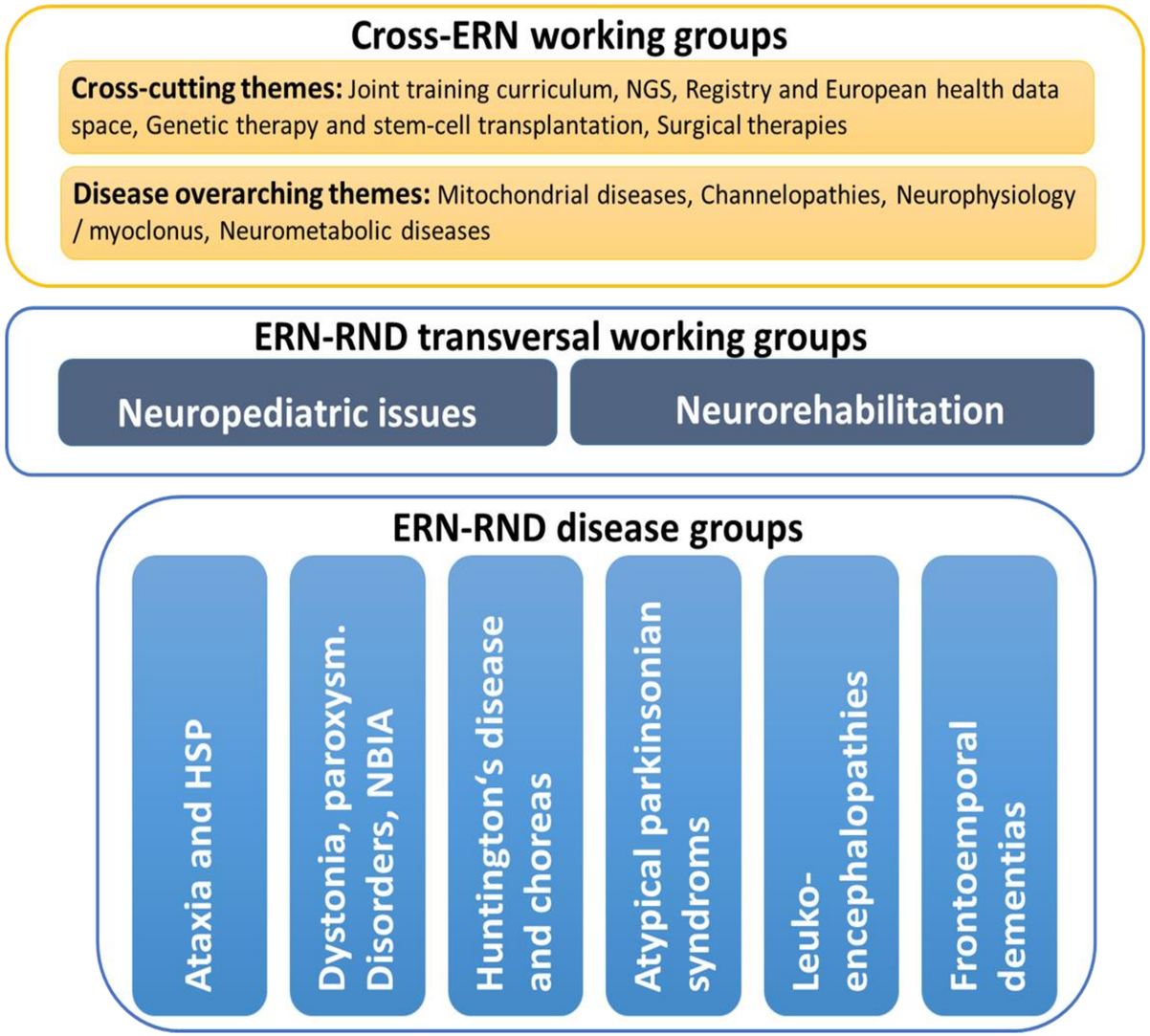
Country	N members
Greece	1
Hungary	3
Ireland	1
Italy	9
Lithuania	1
Netherlands	6
Poland	2
Slovenia	1
Spain	8
Sweden	2

Country	N members
Estonia	1
Latvia	1
Luxembourg	1
Malta	1

Governance

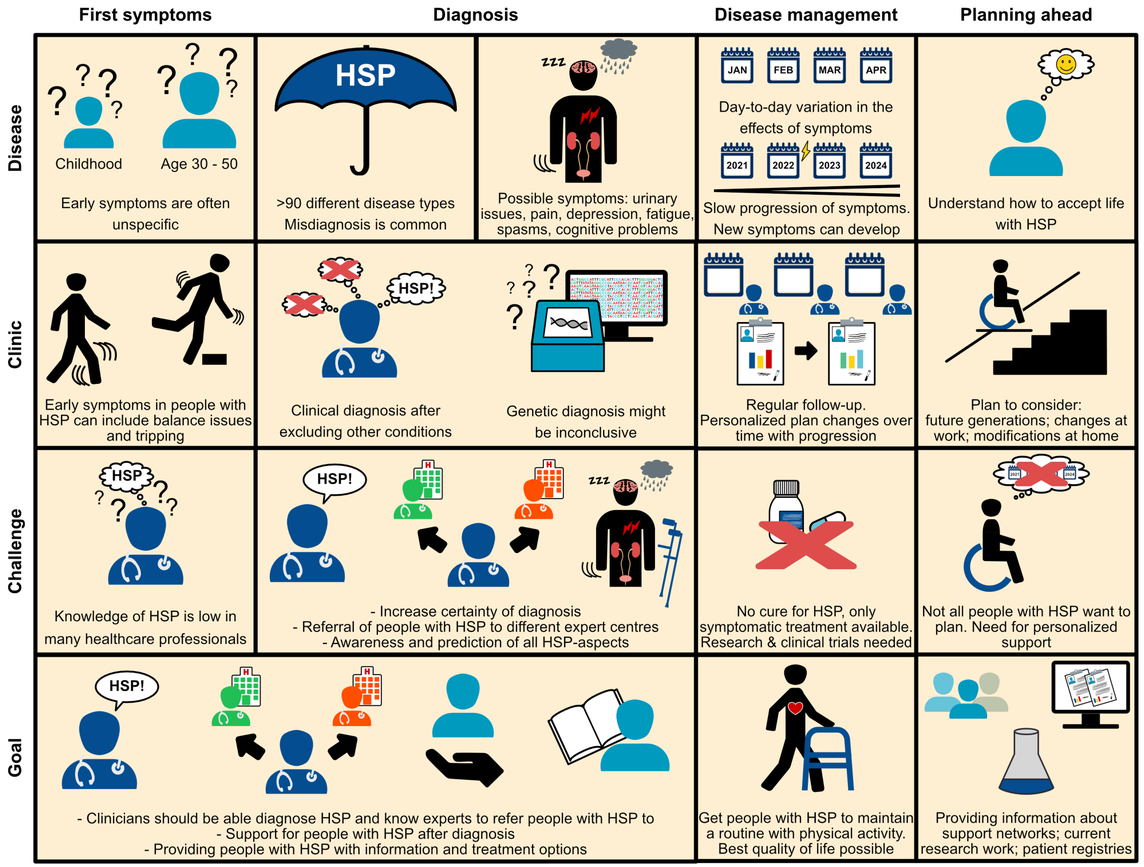
- ERN-RND Board
- ERN-RND ePAG
- ERN-RND Management Team
- ERN-RND Advisory Board
- ERN-RND Coordination Office

- Disease Expert Groups and Working Groups
- Cross-ERN working groups



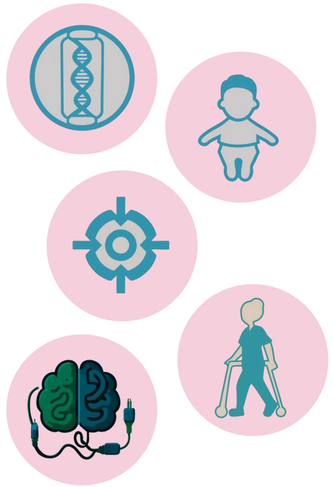
Core activities of ERN-RND

- Crossborder healthcare / CPMS
- Training and education of health professionals
- ERN-RND registry
- Guidelines and Clinical Decision Support Tools / care standards
- Patient journeys
- Dissemination



Example: Patient Journey for Hereditary Spastic Paraplegia

ERN-RND - mode of action for improvement of care equity



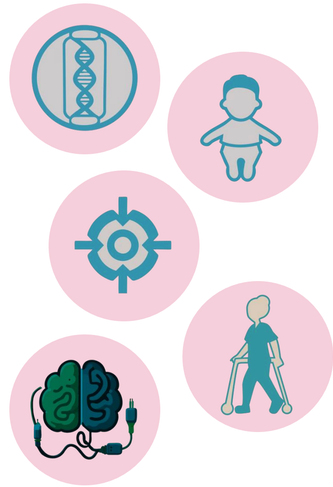
Mapping of care inequalities

Next Generation Sequencing
Neuroimaging
Botulinum toxin treatments
Deep Brain Stimulation
Stem Cell Transplantation
Neurorehabilitation
Intrathecal baclofen
Paediatric (off-label) medication
Genetic therapies
…

Design of intervention(s)

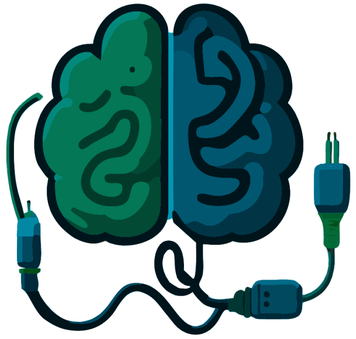
ERN-RND tool-box

Measurement of effect



Cross-Border healthcare pathway: DBS in Dystonia

Standard pathway for harmonizing & optimizing DBS management decisions in Dystonia patients.



Harmonizing care

Consensus on best practice and minimum requirements (standard operating procedure)

Cross-border healthcare

Online multidisciplinary Board for DBS in Dystonia

Online Learning

Expert webinars and post-graduate curriculum

F2F Exchange

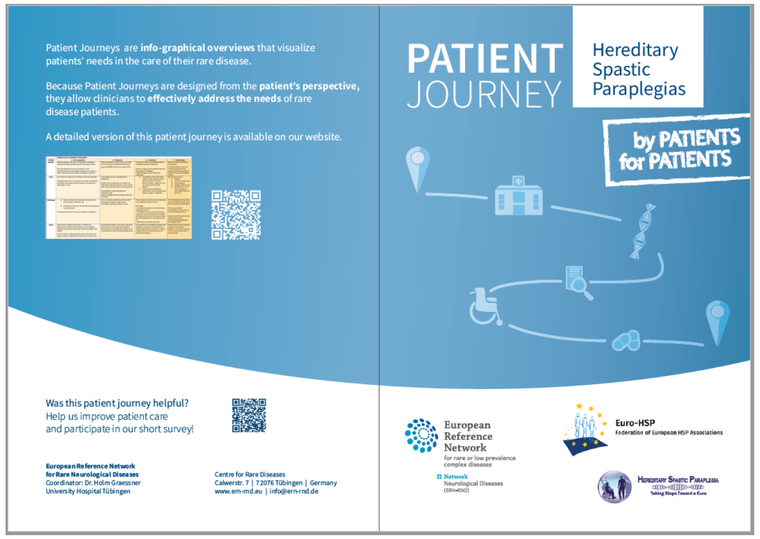
Symposium in Würzburg, Germany 2025

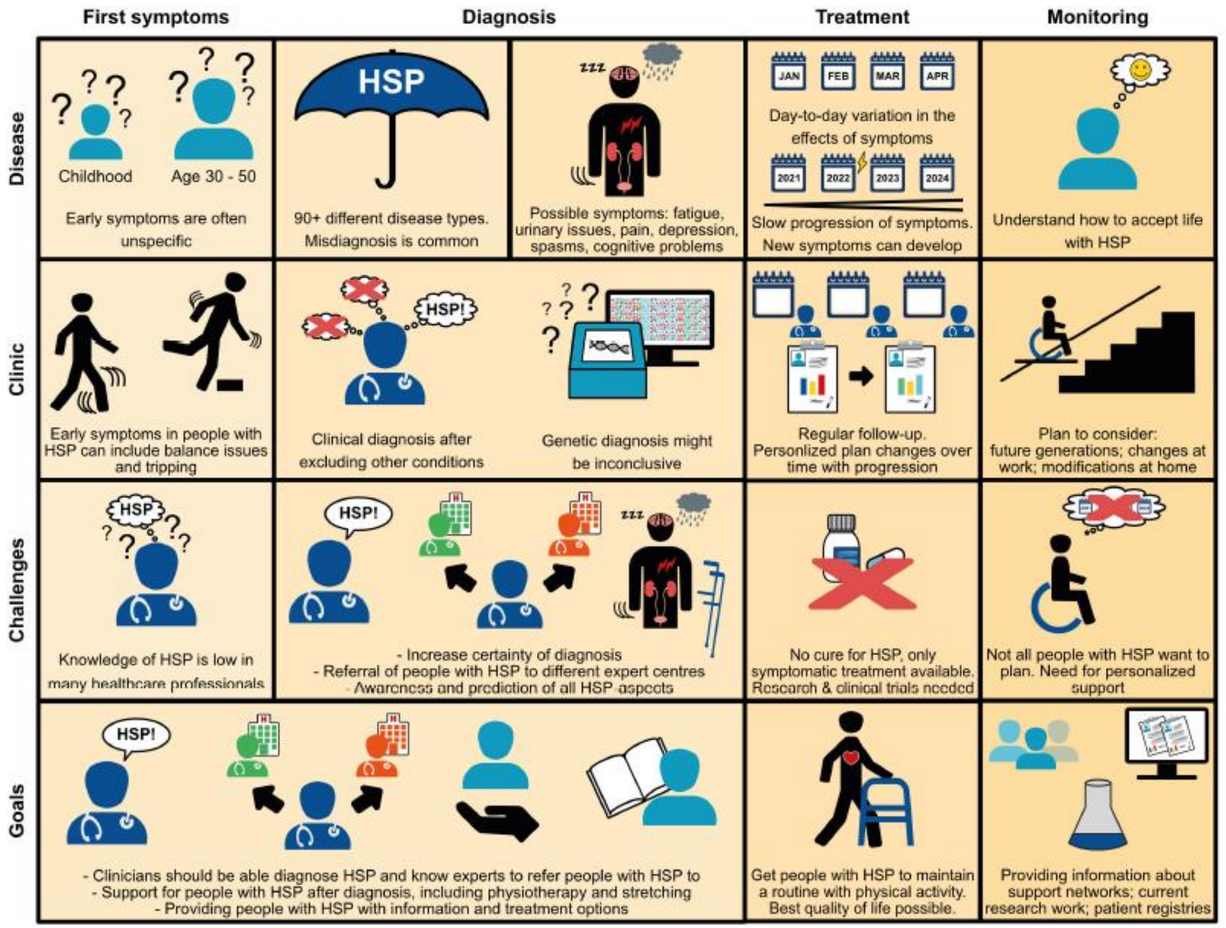
Hands-on training

Exchanges to DBS expert centers

Impact on patient care – Success Story – Patient journeys

- Led by ePAGs
- All ERN-RND disease areas
- Main European languages
- Goal: hand out a suitable patient journey to all newly diagnosed patients





Registry

	2021	2022	2023
No of centers sent data	8	28	37
No of datasets received	1872	4960	7922

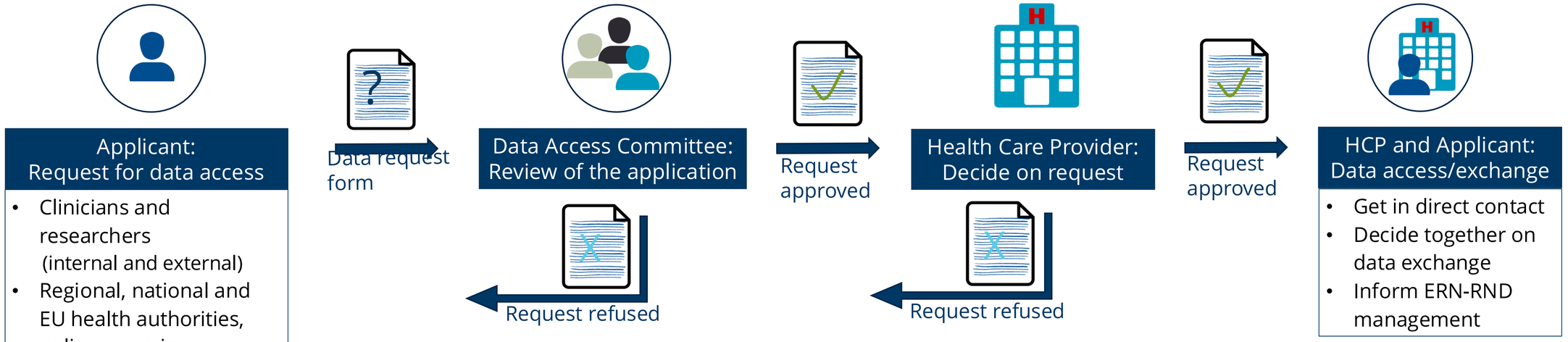
No of centers signed Data Sharing Agreement: 47

Further activities during the last year:

- Data monitoring and upload into the REDCap database
- Data Quality Report for all HCPs who have submitted data
- Data analysis

- Data Access Committee and Process up and running
- Survey of other ERN registries: codification and numbers of patients without determined diagnosis

Data access:



Summary

- ERNs are cross-border collaborative patient-centered networks that bring together European hospital centres of expertise and reference
- ERNs create value for rare, low prevalence and complex diseases and conditions requiring highly specialised healthcare
- ERNs facilitate research

European Reference Networks

Centers of Excellence

SJD Barcelona Children's Hospital

European Reference Networks

Centers of Excellence

NoRo Center
Romania

NoRo Rare Disease Centre

Interview with Dorica Dan, Psychologist, Parent of daughter with Prader-Willi syndrome and Founder of NoRo Center – the Pilot Reference Center for Rare Diseases in Zalău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