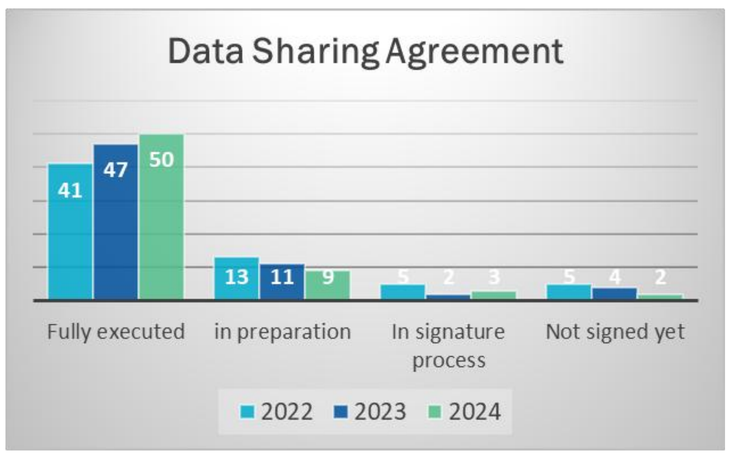
ERN-RND Registry: Collecting data – improving healthcare

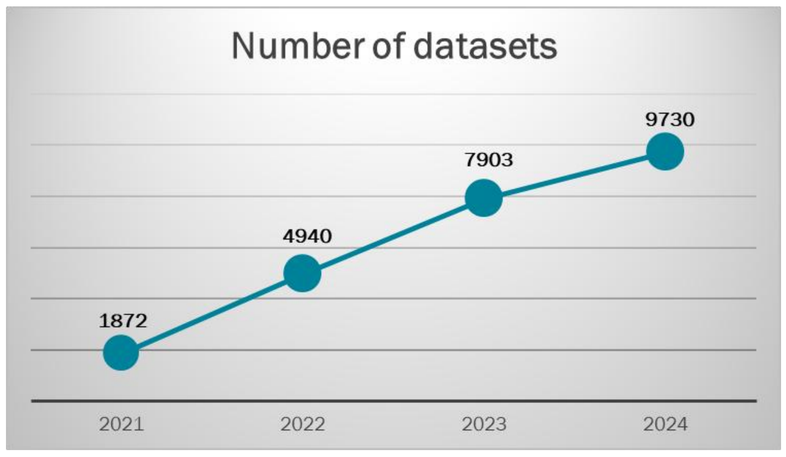
WP5

Registry, data management and analysis

Objectives

- ✓ collect data on patients seen in ERN-RND
- ✓ harmonize data on RND patients across the EU
- ✓ improve healthcare: faster diagnosis, consistent standards
- ✓ make data FAIR: findable, accessible, interoperable, reusable





Registry 2025

18
DATA ELEMENTS

39
HCPs SENT DATA

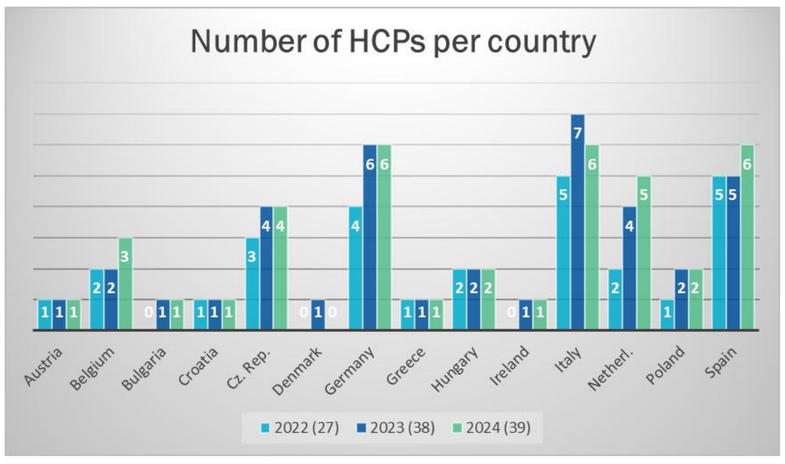
12,000
PATIENTS (cumulative)

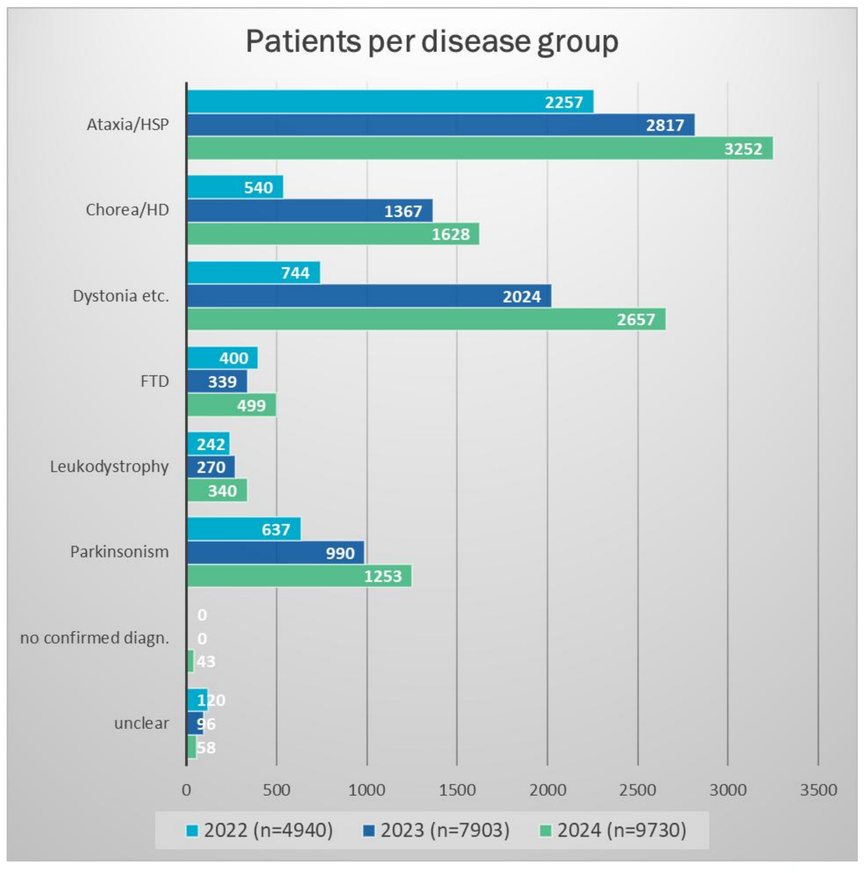
Data management and data access

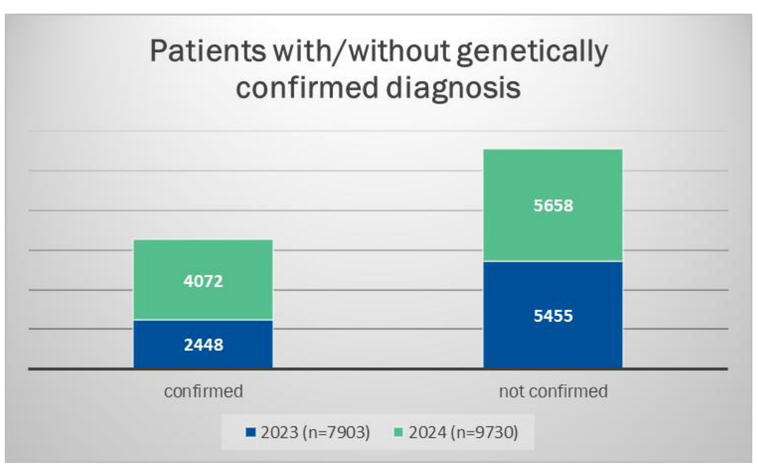
- ✓ Every ERN-RND HCP has to submit **data of all patients that were seen in one full calendar year** in the scope of ERN-RND. This includes patients without a genetically confirmed diagnosis.
- ✓ Clinicians, researchers, health authorities, patient and non-governmental organizations can apply
- ✓ Data access is regulated by the **Data Access Policy** and is possible by applying to the **Data Access Committee (DAC)**

- ✓ The DAC comprises the following **members**: the Clinical Coordinator, one member from each disease group of the ERN, a patient representative
- ✓ **WG automated data transfer (AuDaT)**: interoperability between HCPs and ERN-RND registry

Data analysis







The results of the data analysis (aggregated data) are published annually on the ERN-RND website.

European Reference Network
for rare or low prevalence complex diseases

Network Neurological Diseases (ERN-RND)

Co-funded by the European Union