

ENROL: The European Rare Blood Disorders Platform

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ENROL has been conceived in the core of ERN-EuroBloodNet as an umbrella for both new and already existing registries on rare hematological disorders (RHD) aiming to maximize public benefit from data on RHD in agreement with EU regulations for cross-border sharing of personal data and promoting the standards for patient registries' interoperability.

To connect, upgrade and build EU patient registries on RHDs, while promoting interoperability standards in line with the EU-RD Platform

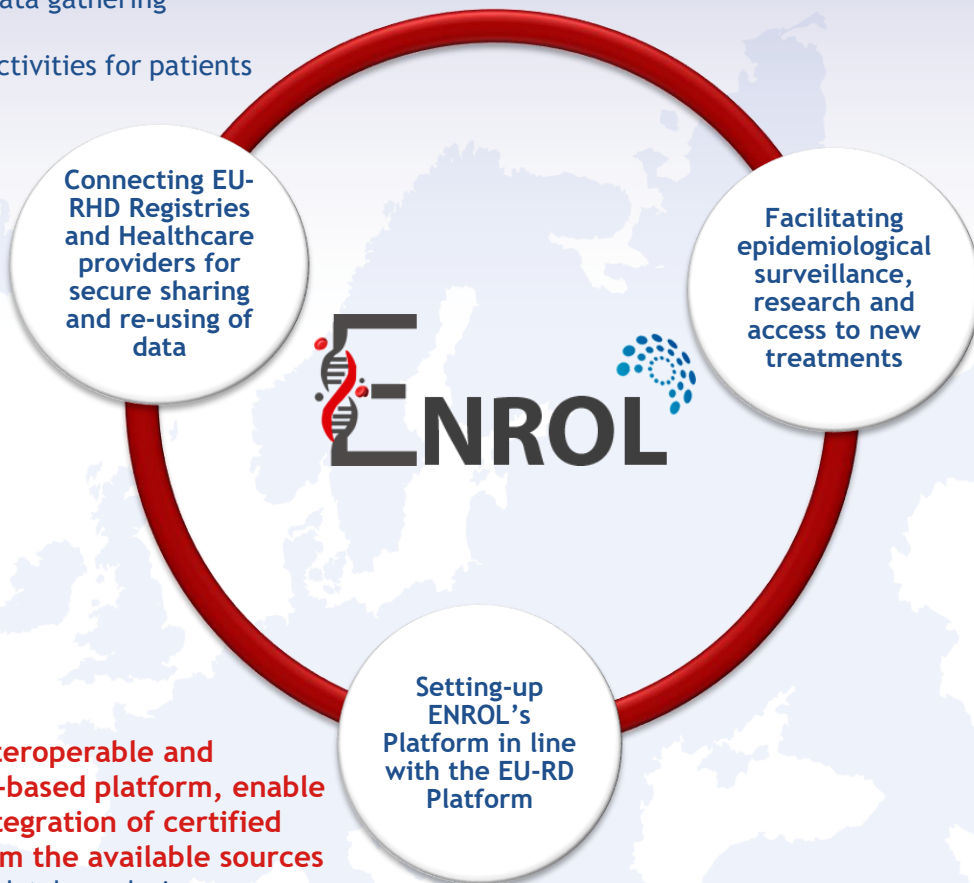
- Inventory of EU-RHD-Registries
- Strategy for data gathering
- Legal frame
- Educational activities for patients

To enable comparable data on RHD at the EU level for epidemiological and clinical surveillance, promoting the engagement of basic and clinical research practices

- Panel of Experts
- Research protocol
- Data set elements & Codification schemes
- Reporting

To create an interoperable and extendible web-based platform, enable entering and integration of certified patient data from the available sources

- Metadata and database design
- Building the platform
- Data integration and processing
- Recommendations for interoperability - EU-RD Platform



Activities for patients will be provided in collaboration with EURORDIS for making patients and families aware about the benefits of enrolment in registries.