

Conceived in the core of ERN-EuroBloodNet for maximizing public benefit from data on rare hematological diseases.



In collaboration with:



What is ENROL?

Target-driven actions will be carried-out in collaboration with EURORDIS for patients empowerment and education about the benefits of enrolment in such registries, including different cultural and linguistic strategies.



ENROL is co-funded by the European Commission - Consumers, Health, Agriculture and Food Executive Agency (CHAFAEA) under the call for proposals HP-PJ-2019 on Rare disease registries for the European Reference Networks. GA number 947670.



ENROL has been conceived in the core of ERN-EuroBloodNet as an umbrella for both new and already existing registries on rare hematological diseases (RHD).

ENROL's principle is to maximize public benefit from data on RHD with the only restriction needed to guarantee patient rights and confidentiality, in agreement with EU regulations for cross-border sharing of personal data.

ENROL will map at the EU level demographics, survival rates, diagnosis methods, genetic information, main clinical manifestations and treatments in order to obtain epidemiological figures and identify trial cohorts for basic and clinical research.

Official dates of ENROL:

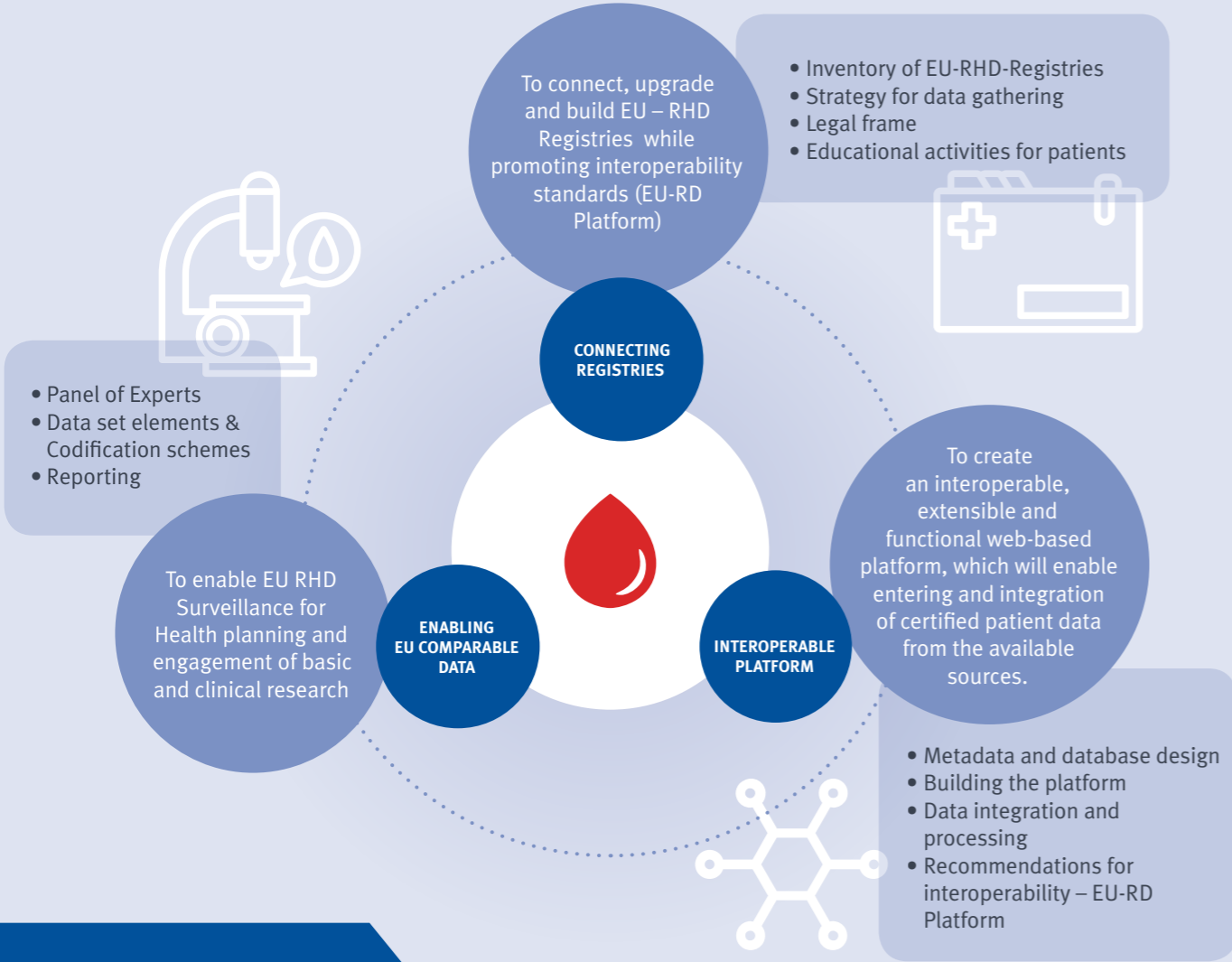


The content of this flyer represents the views of the authors only and it is their sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency (Chafea) or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.

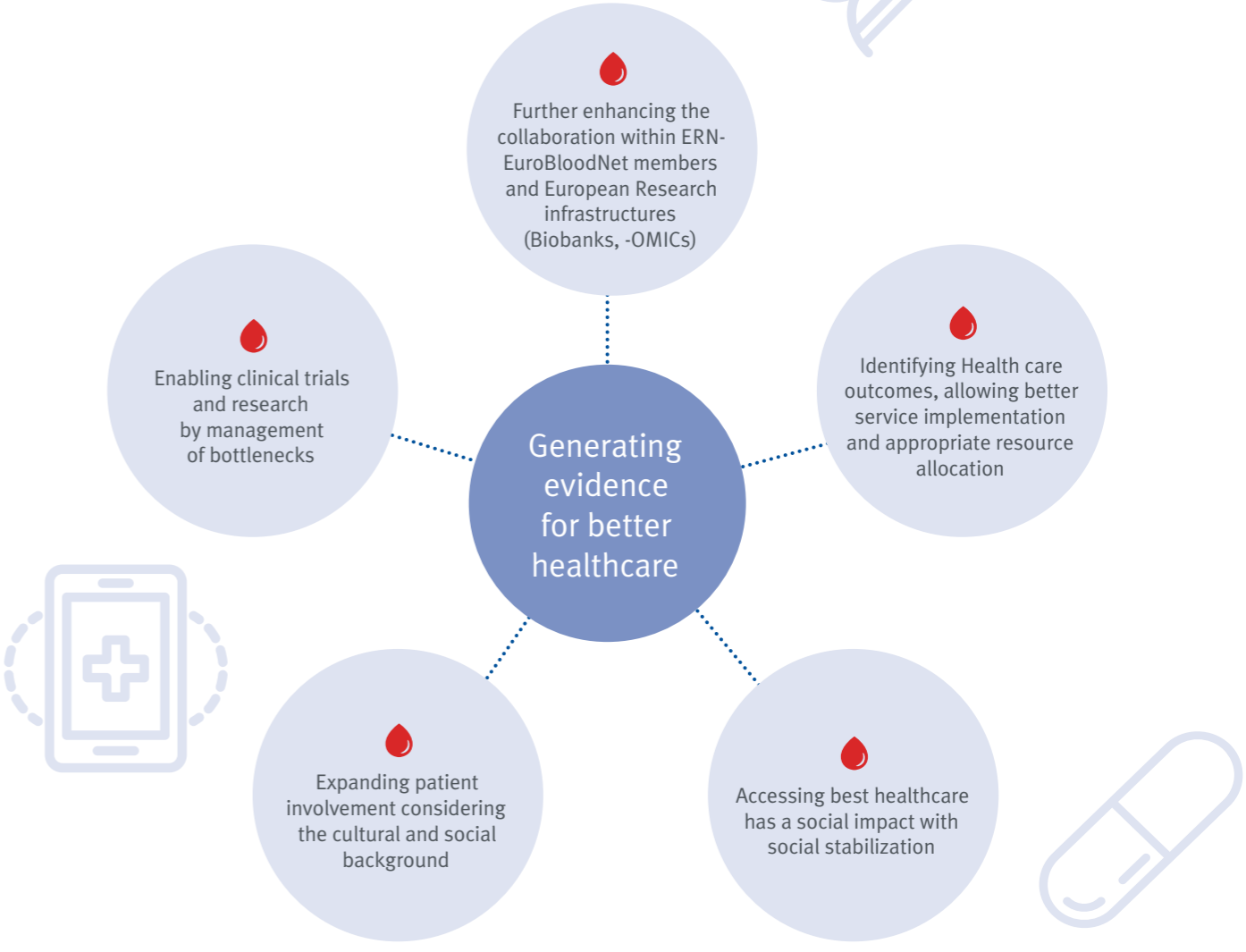
www.eurobloodnet.eu/enrol

Generating evidence towards better healthcare for patients with rare hematological diseases

Objectives and main tasks



Expected outcomes



ENROL Consortium

COORDINATOR

María del Mar Mañú Pereira

Vall d'Hebron University Hospital (HUVH) - Vall d'Hebron University Hospital Foundation - Research Institute (VHIR), Barcelona, Spain

Béatrice Gulbis

Erasmus University Hospital (ERASME) / LHUB-ULB, Brussels, Belgium

Marina Kleanthous

The Cyprus Foundation for muscular dystrophy research (CING), Nicosia, Cyprus

Pierre Fenaux

Assistance Publique - Hopitaux de Paris (AP-HP), Paris, France