

European Rare Blood Disorders Platform

# The Registry Module for the Collection of annual counts of patients with Rare Hematological Disorders - EpiBlood

Survey template - 2025



Hematological
Diseases (ERN EuroBloodNet)



Funded by the European Union

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# Myeloid malignancies

Dear expert,

Thank you so much for collaborating with the ENROL Registry mapping of 2025. Please consider that the edition of the submitted data will be available until the 28<sup>th</sup> of April 2026.

As a reminder, the period to be reported is 1st of January - 31st December 2025.

Your contribution is mandatory for the subnetworks where Member. However, the opportunity to contribute is also ex	
Kinds regards,	
ENROL Coordination team	
Remember to report only numbers on adult patients (≥18 years)	ears old)
Mastocytosis	
Number of new patients referred to the Health Care roviders participating in the ERN diagnosed with this isease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients	
Acute myeloid leukemia	
Number of new patients referred to the Health Care roviders participating in the ERN diagnosed with this isease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and



	Page 2
	visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients	
Acute promyelocitic leukemia	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this lisease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients	
Myeloid neoplasms with germline presdiposition of	or inherited
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this lisease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients	



Page	3
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Myelodysplastic syndrome	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients	



Myeloproliferative neoplasm (Other than Chronic myeloid leukemia and Hypereosinophilic syndrome)		
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this		
disease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)	
Number of new male patients		
Number of new female patients		
Chronic myeloid leukemia		
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this		
disease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)	
Number of new male patients		
Number of new female patients		
Hypereosinophilic syndrome		
Number of new patients referred to the Health Care		
Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)	



Number of new male patients	
Number of new female patients	
Myelodysplastic/myeloproliferative disease	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients	
Myeloid neoplasms associated with eosinophilia FGFR1	and abnormality of PDGFRA, PDGFRB or
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients	
Status of the survey	<ul> <li>Incomplete</li> <li>Unverified</li> <li>Completed</li> <li>(Only surveys marked as 'completed' in this section will be considered in the analysis)</li> </ul>



# Lymphoid malignancies

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Member. However, the opportunity to contribute is also extended to other subnetworks.
Kinds regards,

ENROL Coordination team

Remember to report only numbers on adult patients (≥18 years old)

## Plasma cell neoplasm

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

Number of new male patients	
Number of new female patients	

### AL amyloidosis

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this



disease group

(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

Number of new male patients



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Number of new female patients	
Dendritic cell neoplasm	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients	
Posttransplant lymphoproliferative disorders (PTLD	0)
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients	
Acute lymphoblastic leukemia	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care



	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients	
Follicular lymphoma	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	
	this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients	
Indolent B-cell lymphomas / Non-follicular	
Number of new patients referred to the Health Care	
Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges



	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients	
Hairy cell leukemia	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients  Diffuse large B-cell lymphoma, NOS	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	
	this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	



	(Number of new patients seen at the Health Care
	Provider for the first time during the reporting period, whose disease or condition falls inside
Number of new female patients	
Diffuse large B-cell lymphoma, other than NOS	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients	
Hodgkin Lymphoma	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	



	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside
Number of new female patients  Mantle cell lymphoma	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	
	this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients	
Other agressive B-cell neoplasm	
Number of new patients referred to the Health Care	
Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients	
	<del></del>



	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside
Mature T-cell neoplasm non-primary cutaneous.1 L	Leukemic
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients	



Mature T-cell neoplasm non-primary cutaneous.2 Ex	of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside <b>tra nodal</b>
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this lisease group	(Number
	this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients	
Mature T-cell neoplasm non-primary cutaneous.2	. Nodal
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of new male patients	
Number of new female patients	
Mature T-cell neoplasms primary cutaneous	
Number of new patients referred to the Health Care	



Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)	
Number of new female patients  Castleman disease  Number of new patients referred to the Health Care		
Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)	
Number of new male patients		
Number of new female patients		
Status of the survey	<ul> <li>Incomplete</li> <li>Unverified</li> <li>Completed</li> <li>(Only surveys marked as 'completed' in this section will be considered in the analysis)</li> </ul>	



# Red blood cell defects

Dear expert,

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the submitted data will be available until the 28th of April 2026.	

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ENROL Coordination team	
Remember: Pediatric patients are those < 18 years old,	while adults are those ≥18 years old.
Autoinmune hemolytic anemia	
Number of total patients referred to the Health Care Prowith this	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	

Number of new patients referred to the Health Care



Providers participating in the ERN diagnosed with this disease group

**Health Care** 

(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)



Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
Alpha-thalassemia and related diseases	
Number of total patients referred to the Health Care Provide	ers participating in the ERN diagnosed
with thisdisease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

Number of new pediatric patients



Number of new adult patients	
Number of new male patients	
Number of new female patients	
Beta-thalassemia and related diseases	
Number of total patients referred to the Health Care Provide with this	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

Number of new pediatric patients



Number of new adult patients	
Number of new male patients	
Number of new female patients	
Sickle cell disease and related diseases	
Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	

Number of new adult patients

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Number of new male patients	
Trainiber of her mate patients	
Number of new female patients	
Hemoglobinopathy (Other than thalassaemia and sic	kle cell disease)
Number of total patients referred to the Health Care Providers	mic cen discuse)
participating in the ERN diagnosed with this	
disease group	(Number of total patients seen at the Health Care
	Provider during the reporting period (no matter if
	they come for the first time or not), whose disease
	or condition falls inside this group of diseases, whatever their age, including visits to outpatient's
	clinics, hospital discharges and emergencies, coming
	from national and international referrals)
Number of pediatric patients	
No. 1 and a first throughout	
Number of adult patients	
Number of male patients	
•	
Number of female patients	
Note that the second se	
Number of new patients referred to the Health Care	
Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care
inscuse group	Providers for the first time during the reporting
	period, whose disease or condition falls inside this
	group of diseases, whatever their age, including
	new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from
	national and international referrals.)
Number of new podiatric nationts	
Number of new pediatric patients	
Number of new adult patients	



Number of new male patients	
Number of new female patients	
Hereditary spherocytosis	
Number of total patients referred to the Hea with this	lth Care Providers participating in the ERN diagnosed
disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases,

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whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming

from national and international referrals)

Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
Hereditary elliptocytosis	
Number of total patients referred to the Health Care Providers pa	articipating in the ERN diagnosed
with this disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)



Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care	
Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care
	Providers for the first time during the reporting
	period, whose disease or condition falls inside this group of diseases, whatever their age, including
	new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming
	from national and international referrals.)
Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
- Constitution of the Cons	
Hereditary stomatocytosis	
Number of total patients referred to the Health Care Providers with this	s participating in the ERN diagnosed
disease group	(Number of total patients seen at the Health Care
	Provider during the reporting period (no matter if they come for the first time or not), whose disease
	or condition falls inside this group of diseases,
	whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming
	from national and international referrals)
Number of pediatric patients	



Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care	
Providers participating in the ERN diagnosed with this	
disease group	(Number of new patients seen at the Health Care
3. out	Providers for the first time during the reporting
	period, whose disease or condition falls inside this
	group of diseases, whatever their age, including
	new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming
	from national and international referrals.)
Number of new pediatric patients	
Number of new adult patients	
The state of the s	
Number of new male patients	
The state of the s	
Number of new female patients	
Rare constitutional hemolytic anemia due to a red co	ell membrane anomaly (Other than
· · · · · · · · · · · · · · · · · · ·	• •
Hereditary Spherocytosis, Hereditary elliptocytosis,	Hereditary Stomatocytosis)
Number of total patients referred to the Health Care	
Providers participating in the ERN diagnosed with this	
disease group	(Number of total patients seen at the Health Care
	Provider during the reporting period (no matter if
	they come for the first time or not), whose disease
	or condition falls inside this group of diseases, whatever their age, including visits to outpatient's
	clinics, hospital discharges and emergencies, coming
	from national and international referrals)
	,

Number of pediatric patients

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Number of adult patients	
Number of addic pacients	
Number of male patients	
Number of mate patients	
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Number of formal a national	
Number of female patients	
Number of new patients referred to the Health Care	
Providers participating in the ERN diagnosed with this	(Number of new neticute seem at the Health Com-
lisease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting
	period, whose disease or condition falls inside this
	group of diseases, whatever their age, including
	new diagnosis and visits to outpatient's clinics,
	hospital discharges and emergencies, coming from national and international referrals.)
	Number of new pediatric patients
Number of new adult patients	
Trainber of her addit patients	
	<del></del>
Number of new male patients	
Number of new mate patients	
Number of new female patients	
Number of flew remate patients	
	<del></del>
Rare constitutional hemolytic anemia due to pyr	uvate kinase deficiency (PKD)
Number of total patients referred to the Health Care Provide	ders participating in the ERN diagnosed
with this	
disease group	(Number of total patients seen at the Health Care
	Provider during the reporting period (no matter if
	they come for the first time or not), whose disease
	or condition falls inside this group of diseases,
	whatever their age, including visits to outpatient's
	clinics, hospital discharges and emergencies, coming from national and international referrals)
	nom national and international referrats)
Number of podiatric patients	
Number of pediatric patients	
Number of adult patients	
maniper or addit patients	



Number of male patients	
Number of mate patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this	
disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
Rare constitutional hemolytic anemia due to an	enzyme disorder (Other than PKD)
Number of total patients referred to the Health Care Providence of total patients referred to the Health Care Providence of total patients referred to the Health Care Providence of total patients referred to the Health Care Providence of total patients referred to the Health Care Providence of total patients referred to the Health Care Providence of total patients referred to the Health Care Providence of total patients referred to the Health Care Providence of total patients referred to the Health Care Providence of total patients referred to the Health Care Providence of total patients referred to the Health Care Providence of total patients referred to the Health Care Providence of total patients referred to the Health Care Providence of total patients referred to the Health Care Providence of total patients referred to the Health Care Providence of total patients referred to the Health Care Providence of total patients referred to the Health Care Providence of total patients referred to the Health Care Providence of total patients referred to the Health Care Providence of the Health Care Provide	ders participating in the ERN diagnosed
with this disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	



Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
Status of the survey	<ul> <li>Incomplete</li> <li>Unverified</li> <li>Completed</li> <li>(Only surveys marked as 'completed' in this section will be considered in the analysis)</li> </ul>



# **Bleeding-Coagulation disorders**

Dear expert,

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Kinds regards,	
ENROL Coordination team	
Remember: Pediatric patients are those < 18 years old, while adu	ılts are those ≥18 years old
Typical hemolytic-uremic syndrome	
Number of total patients referred to the Health Care Providers pa with this disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this



	group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
Atypical hemolytic-uremic syndrome	
Number of total patients referred to the Health Care Provid with this	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)



Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
Rare hemorrhagic disease due to coagulation fac	tors defects (Other than hemophilia and
Number of total patients referred to the Health Care Provide	ers participating in the ERN diagnosed
with thisdisease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)



Provider during the reporting period (no mathey come for the first time or not), whose or condition falls inside this group of disease whatever their age, including visits to output clinics, hospital discharges and emergencies from national and international referrals)  Number of pediatric patients  Number of adult patients  Number of male patients  Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group  (Number of new patients seen at the Health Providers for the first time during the reperiod, whose disease or condition falls insignoup of diseases, whatever their age, in new diagnosis and visits to outpatient's conspital discharges and emergencies, comin		
Number of new male patients    Number of new female patients	Number of new pediatric patients	
Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group  (Number of total patients seen at the Health Provider during the reporting period (no mathey come for the first time or not), whose or condition falls inside this group of disease whatever their age, including visits to output clinics, hospital discharges and emergencies from national and international referrals)  Number of pediatric patients  Number of male patients  Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group  (Number of new patients seen at the Health Providers for the first time during the reperiod, whose disease or condition falls insignoup of diseases, whatever their age, inchew diagnosis and visits to outpatients of hospital discharges and emergencies, comin	Number of new adult patients	·
Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group  (Number of total patients seen at the Health Provider during the reporting period (no mathey come for the first time or not), whose or condition falls inside this group of disease whatever their age, including visits to outpatients whatever their age, including visits to outpatients  Number of pediatric patients  Number of adult patients  Number of male patients  Number of male patients  Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group  (Number of new patients seen at the Health Providers for the first time during the reporting period (no mathey come for the first time or not), whose disease or condition falls insignoup of diseases, whatever their age, including visits to outpatients and visits to outpatients of the period of the period of the patients and visits to outpatients and visits to outpatients of the period o	Number of new male patients	
Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group    Number of total patients seen at the Health Provider during the reporting period (no mathey come for the first time or not), whose or condition falls inside this group of disease whatever their age, including visits to output clinics, hospital discharges and emergencies from national and international referrals)    Number of pediatric patients	Number of new female patients	
Providers participating in the ERN diagnosed with this disease group  (Number of total patients seen at the Health Provider during the reporting period (no mathey come for the first time or not), whose or condition falls inside this group of disease whatever their age, including visits to outpatients clinics, hospital discharges and emergencies from national and international referrals)  Number of pediatric patients  Number of adult patients  Number of male patients  Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group  (Number of new patients seen at the Health Providers for the first time during the reperiod, whose disease or condition falls insignoup of diseases, whatever their age, inc new diagnosis and visits to outpatient's chospital discharges and emergencies, comin	Hemophilia A	
Number of adult patients  Number of male patients  Number of female patients  Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group  (Number of new patients seen at the Health Providers for the first time during the reperiod, whose disease or condition falls insignoup of diseases, whatever their age, indonew diagnosis and visits to outpatient's a hospital discharges and emergencies, comin	Providers participating in the ERN diagnosed with this	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of male patients  Number of female patients  Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group  (Number of new patients seen at the Health Providers for the first time during the reperiod, whose disease or condition falls insignoup of diseases, whatever their age, income diagnosis and visits to outpatient's chospital discharges and emergencies, comin	Number of pediatric patients	
Number of female patients  Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group  (Number of new patients seen at the Health Providers for the first time during the repperiod, whose disease or condition falls insignation group of diseases, whatever their age, income diagnosis and visits to outpatient's chospital discharges and emergencies, comin	Number of adult patients	
Number of new patients referred to the Health Care  Providers participating in the ERN diagnosed with this disease group  (Number of new patients seen at the Health Providers for the first time during the repperiod, whose disease or condition falls insignate group of diseases, whatever their age, income diagnosis and visits to outpatient's chospital discharges and emergencies, comin	Number of male patients	
Providers participating in the ERN diagnosed with this  disease group  (Number of new patients seen at the Health Providers for the first time during the rep period, whose disease or condition falls insi group of diseases, whatever their age, inc new diagnosis and visits to outpatient's of hospital discharges and emergencies, comin	Number of female patients	
	Providers participating in the ERN diagnosed with this	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

Number of new pediatric patients



Number of new adult patients	
Number of new addit patients	
Number of new male patients	
Number of new female patients	
Hemophilia B	
Number of total patients referred to the Health Care Providers	
participating in the ERN diagnosed with this disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this	
disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	



Number of new adult patients	
Number of new male patients	
Number of new female patients	
Von Willebrand Disease	
Number of total patients referred to the Health Care Providers pa	articipating in the ERN diagnosed
disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
Rare hemorrhagic disorder due to a constitutional plant Number of total patients referred to the Health Care Providers patients	,
with thisdisease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)



Number of pediatric patients		
Number of adult patients		
Number of male patients		
		Page 7
Number of female patients		
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease gro		
	Health C for the during t period, v or condit: this grou whatever including diagnosis outpatier hospital c emergence	new and visits to at's clinics, discharges and cies, coming ational and onal
Number of new pediatric patients		
Number of new adult patients		
Number of new male patients		
Number of new female patients		

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Rare hemorrhagic disorder due to an acquired pla	atelet anomaly	
Number of total patients referred to the Health Care Providents with this	ers participating in the ERN diagnosed	
disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, comi from national and international referrals)	
Number of pediatric patients		
Number of adult patients		
Number of male patients		
Number of female patients		
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)	
Number of new pediatric patients		
Number of new adult patients		
Number of new male patients		
Number of new female patients		



Rare thrombotic disorder due to a coagulation factor.  Number of total patients referred to the Health Care Providers		
with thisdisease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, comin from national and international referrals)	
Number of pediatric patients		
Number of adult patients		
Number of male patients		
Number of female patients		
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)	



Number of new pediatric patients		
Number of new adult patients		
Number of new male patients		
Number of new female patients		
Rare thrombotic disorders due to a quantitative p	platelet anomaly (Low)	
Number of total patients referred to the Health Care Provide	<u> </u>	
with this disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, comin from national and international referrals)	
Number of pediatric patients		
Number of adult patients		
Number of male patients		
Number of female patients		
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)	



Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
Rare thrombotic disorders due to a quantitative	platelet anomaly (High)
Number of total patients referred to the Health Care Provide with this disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics,



hospital discharges and emergencies, coming from national and international referrals.)

Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
Status of the survey	Incomplete Unverified Completed (Only surveys marked as 'completed' in this section will be considered in the analysis)
Bone marrow failure and he	ematopoietic disorders
Dear expert,	
Thank you so much for collaborating with the ENRO the submitted data will be available until the 28st of	OL Registry mapping of 2025. Please consider that the edition of of April 2026.
As a reminder, the <b>period to be reported is 1st of</b>	January - 31st December 2025.
Your contribution is mandatory for the subnetworks Member. However, the opportunity to contribute is	s where your institution is nationally recognized as an ERN salso extended to other subnetworks.
Kinds regards,	
ENROL Coordination team	
Remember: Pediatric patients are those < 18 years	old, while adults are those ≥18 years old
Paroxysmal nocturnal hemoglobinuria	
Number of total patients referred to the Health Car	re Providers participating in the ERN diagnosed
with thisdisease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases,



	whatever their age, including visits to outpatient's clinics, hospita	
	discharges and emergencies, coming from national and international referrals)	
Number of pediatric patients		
Number of adult patients		
Number of male patients		
Number of female patients		
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this		
disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)	

Number of new pediatric patients		
Number of new adult patients		
Number of new male patients		
Number of new female patients		
Blackfan - Diamond Anemia  Number of total patients referred to the Health Care Provider	rs participating in the EDN diagnosed	
with thisdisease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, comir from national and international referrals)	
Number of pediatric patients		
Number of adult patients		
Number of male patients		
Number of female patients		
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)	

Number of new pediatric patients



Number of new adult patients		
Number of new male patients		
Number of new female patients		
Dyskeratosis congenita and related disorders		
Number of total patients referred to the Health Care Providers parts with this	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, comin from national and international referrals)	
Number of pediatric patients		
Number of adult patients		
Number of male patients		
Number of female patients		
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)	

Number of new pediatric patients



Number of new adult patients	
Number of new male patients	
Number of new female patients	
Fanconi Anemia	
Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	
	<del></del>

Number of new adult patients

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	<del></del>
Number of new male patients	
Number of new female patients	
Rare constitutional aplastic anemia (Other than BDA	, FA, SD)
Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care
insease group	Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	
Number of new adult patients	



Number of new male patients	
Number of new female patients	
Shwachman-Diamond syndrome	
Number of total patients referred to the Health Care with this	Providers participating in the ERN diagnosed
disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease

Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
Idiopathic Aplastic Anemia	
Number of total patients referred to the Health Care Providers p	participating in the ERN diagnosed
with this disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)



Number of pediatric patients		
Number of adult patients		
Number of male patients		
		Page 7
Number of female patients		
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease gro	oud	
	(Number patients) Health for the during period, or condithis growhateve including diagnosity outpatien hospital emerger	care Providers e first time the reporting whose disease ition falls inside up of diseases, er their age, is and visits to ent's clinics, discharges and ncies, coming national
Number of new pediatric patients		
Number of new adult patients		
Number of new male patients		-
Number of new female patients		

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Red Cell Aplasia	
Number of total patients referred to the Health Care Provid with this	lers participating in the ERN diagnosed
disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	



Number of new female patients	
Constitutional Megaloblastic Anemia	
Number of total patients referred to the Health Care Provi	ders participating in the ERN diagnosed
disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, comin from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)



Number of new pediatric patients		
Number of new adult patients		
Number of new male patients		
Number of new female patients		
Congenital dyserythropoietic anemia type II		
Number of total patients referred to the Health Care Provide	ders participating in the ERN diagnosed	
with this disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, comifrom national and international referrals)	
Number of pediatric patients		
Number of adult patients		
Number of male patients		
Number of female patients		
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)	



Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
Congenital dyserythropoietic anemia (Other tha	n type II)
Number of total patients referred to the Health Care Provid	lers participating in the ERN diagnosed
with thisdisease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this	
disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics.



hospital discharges and emergencies, coming from national and international referrals.)

Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
Status of the survey	<ul> <li>Incomplete</li> <li>Unverified</li> <li>Completed</li> <li>(Only surveys marked as 'completed' in this section will be considered in the analysis)</li> </ul>
Hemochromatosis and other iron	related disorders
Dear expert,	
Thank you so much for collaborating with the ENROL Registry the submitted data will be available until the 28th of April 20.	
As a reminder, the <b>period to be reported is 1st of January</b> -	31st December 2025.
Your contribution is mandatory for the subnetworks where you Member. However, the opportunity to contribute is also exten	
Kinds regards,	
ENROL Coordination team	
Remember: Pediatric patients are those < 18 years old, while	adults are those ≥18 years old
Acquired idiopathic sideroblastic anemia	
Number of total patients referred to the Health Care Provider with this	s participating in the ERN diagnosed
disease group	(Number of total patients seen at the Health Care



	Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care	
Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)



Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
Constitutional sideroblastic anemia (Other than ringed sideroblastic)	Severe congenital hypochromic anemia with
Number of total patients referred to the Health Care	
Providers participating in the ERN diagnosed with this disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)



Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
Congenital atransferrinemia	
Number of total patients referred to the Health Care Provide	ers participating in the ERN diagnosed
with this disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	



Number of new adult patients	
Number of new male patients	
Number of new female patients	
Aceruloplasminemia	
Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	



Number of new female patients	
Microcytic anemia with liver iron overload	
Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this	
disease group	(Number of total patients seen at the Health Care
	Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's
	clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	
Number of adult patients	
Number of addit patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care	
Providers participating in the ERN diagnosed with this	
disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
number of new mate patients	



Number of new female patients	

disease group

IRIDA syndrome
Number of total patients referred to the Health Care Providers participating in the ERN diagnosed
with this

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)



Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
Severe congenital hypochromic anemia with ringed sometimes of total patients referred to the Health Care Providers patients.	
with thisdisease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)



Number of pediatric patients	
Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this	
disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
Rare Adquired deficiency anemia (Plummer - Vins	
Number of total patients referred to the Health Care Provide with this	ers participating in the ERN diagnosed
disease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	



Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this lisease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
HFE related hereditary hemochromatosis (Symposium 235201)	tomatic form of hemochromatosis type 1 -
Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this lisease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	



Number of adult patients	
Number of addit patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care	
roviders participating in the ERN diagnosed with this	
isease group	(Number of new patients seen at the Health Care
	Providers for the first time during the reporting period, whose disease or condition falls inside this
	group of diseases, whatever their age, including
	new diagnosis and visits to outpatient's clinics,
	hospital discharges and emergencies, coming from national and international referrals.)
	Number of new pediatric patients
	namber of her pediatric patients
Number of new adult patients	
Number of new male patients	
Number of new female patients	
HFE related hereditary hemochromatosis (Other	than type 1)
Number of total patients referred to the Health Care Provi	iders participating in the ERN diagnosed
with this	
isease group	(Number of total patients seen at the Health Care
	Provider during the reporting period (no matter if
	they come for the first time or not), whose disease
	or condition falls inside this group of diseases, whatever their age, including visits to outpatient's
	clinics, hospital discharges and emergencies, coming
	from national and international referrals)
Number of pediatric patients	
Number of adult patients	



Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care	
Providers participating in the ERN diagnosed with this	
disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
Porphyria	
Number of total patients referred to the Health Care Provide	ders participating in the ERN diagnosed
with thislisease group	(Number of total patients seen at the Health Care Provider during the reporting period (no matter if
	they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)
Number of pediatric patients	



Number of adult patients	
Number of male patients	
Number of female patients	
Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group	(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)
Number of new pediatric patients	
Number of new adult patients	
Number of new male patients	
Number of new female patients	
Status of the survey	<ul> <li>Incomplete</li> <li>Unverified</li> <li>Completed</li> <li>(Only surveys marked as 'completed' in this section will be considered in the analysis)</li> </ul>

