Education and Training Activities

Instructions

List all training activities that were delivered by the HCP's multidisciplinary team in 2025.

- Activities may include online or physical presentations, courses, webinars, preceptorships and/or videos.
- If the same content was delivered multiple times, this only counts as 1 activity.

Eligibility criteria for the Continuous Monitoring

- ERN-EuroBloodNet logo must be present in the Evidence.
- Materials should be made public and available.
- If accredited, the accreditation body must have recognized capacity at regional, national, EU or international level to issue educational credits to healthcare professionals.

Do you have any Education/Training activities to report?	◯ Yes ◯ No
Please enter the Education and Training activity number: [current-instance]	
HCP Survey	_____
Subnetowork 'Red Blood Cell Defects'	_____
Subnetwork 'Bone Marrow Failure'	_____
Subnetwork 'Hematochromatosis and Other Iron Disorders'	_____
Subnetwork 'Bleeding - Coagulation Disorders'	_____
Subnetwork 'Lymphoid Malignancies'	_____
Subnetwork 'Myeloid Malignancies'	_____
Subnetworks covered	◯ All RHDs ◯ Red Blood Cell Defects ◯ Bone Marrow Failure ◯ Hematochromatosis and Other Iron Disorders ◯ Bleeding - Coagulation Disorders ◯ Lymphoid Malignancies ◯ Myeloid Malignancies
Diseases covered values	_____

Disease Group from subnetwork "Red Blood Cell Defects"	◯ Alpha-thalassemia and related diseases ◯ Autoinmune hemolytic anemia ◯ Beta-thalassemia and related diseases ◯ Hemoglobinopathy (Other than thalassaemia and sickle cell disease) ◯ Hereditary elliptocytosis ◯ Hereditary spherocytosis ◯ Hereditary stomatocytosis ◯ Rare constitutional hemolytic anemia due to a red cell membrane anomaly (Other than Hereditary Spherocytosis, Hereditary elliptocytosis, Hereditary Stomatocytosis) ◯ Rare constitutional hemolytic anemia due to an enzyme disorder (Other than PKD) ◯ Rare constitutional hemolytic anemia due to pyruvate kinase deficiency (PKD) ◯ Sickle cell disease and related diseases ◯ It covers all "Red Blood Cell Defects" disease groups
Disease Group from subnetwork "Red Blood Cell Defects" values	_____
Disease Group from subnetwork "Bone Marrow Failure"	◯ Blackfan-Diamond Anemia ◯ Congenital dyserythropoietic anemia (Other than type II) ◯ Congenital dyserythropoietic anemia type II ◯ Constitutional Megaloblastic Anemia ◯ Dyskeratosis congenita and related disorders ◯ Fanconi Anemia ◯ Idiopathic Aplastic Anemia ◯ Paroxysmal nocturnal hemoglobinuria ◯ Rare constitutional aplastic anemia (Other than BDA, FA, SD) ◯ Red Cell Aplasia ◯ Shwachman-Diamond syndrome ◯ It covers all "Bone Marrow Failure" disease groups
Disease Group from subnetwork "Bone Marrow Failure" values	_____
Disease Group from subnetwork "Hematochromatosis and Other Iron Disorders"	◯ Aceruloplasminemia ◯ Acquired idiopathic sideroblastic anemia ◯ Congenital atransferrinemia ◯ Constitutional sideroblastic anemia (Other than Severe congenital hypochromic anemia with ringed sideroblastic) ◯ Rare hereditary hemochromatosis (Other than Type 1) ◯ HFE related hereditary hemochromatosis (Symptomatic form of hemochromatosis type 1 - OMIM 235201) ◯ IRIDA syndrome ◯ Microcytic anemia with liver iron overload ◯ Porphyria ◯ Rare Adquired deficiency anemia (Plummer - Vinson syndrome) ◯ Severe congenital hypochromic anemia with ringed sideroblasts ◯ It covers all "Hematochromatosis and Other Iron Disorders" disease groups
Disease Group from subnetwork "Hematochromatosis and Other Iron Disorders" values	_____

Disease Group from subnetwork "Bleeding - Coagulation Disorders"	◯ Atypical hemolytic-uremic syndrome ◯ Hemophilia A ◯ Hemophilia B ◯ Rare hemorrhagic disease due to coagulation factors defects (Other than Hemophilia and VWD) ◯ Rare hemorrhagic disorder due to a constitutional platelet anomaly ◯ Rare hemorrhagic disorder due to an acquired platelet anomaly ◯ Rare thrombotic disorder due to a coagulation factors defect ◯ Rare thrombotic disorder due to quantitative platelet anomaly (High) ◯ Rare thrombotic disorders due to a quantitative platelet anomaly (Low) ◯ Typical hemolytic-uremic syndrome ◯ Von Willebrand Disease ◯ It covers all "Bleeding - Coagulation Disorders" disease groups
Disease Group from subnetwork "Bleeding - Coagulation Disorders" values	_____
Disease Group from subnetwork "Lymphoid Malignancies"	◯ Acute lymphoblastic leukemia ◯ AL amyloidosis ◯ Castleman disease ◯ Dendritic cell neoplasm ◯ Diffuse large B-cell lymphoma, NOS ◯ Diffuse large B-cell lymphoma, other than NOS ◯ Follicular lymphoma ◯ Hairy cell leukemia ◯ Hodgkin Lymphoma ◯ Indolent B-cell lymphomas / Non-follicular ◯ Mantle cell lymphoma ◯ Mature T-cell neoplasm non-primary cutaneous.1 Leukemic ◯ Mature T-cell neoplasm non-primary cutaneous.2 Extra nodal ◯ Mature T-cell neoplasm non-primary cutaneous.2 Nodal ◯ Mature T-cell neoplasms primary cutaneous ◯ Other agressive B-cell neoplasm ◯ Plasma cell neoplasm ◯ Posttransplant lymphoproliferative disorders (PTLD) ◯ It covers all "Lymphoid Malignancies" disease groups
Disease Group from subnetwork "Lymphoid Malignancies" values	_____

Disease Group from subnetwork "Myeloid Malignancies"	◯ Acute myeloid leukemia ◯ Acute promyelocitic leukemia ◯ Chronic myeloid leukemia ◯ Hypereosinophilic syndrome ◯ Mastocytosis ◯ Myelodysplastic syndrome ◯ Myelodysplastic/myeloproliferative disease ◯ Myeloid neoplasms associated with eosinophilia and abnormality of PDGFRA, PDGFRB or FGFR1 ◯ Myeloid neoplasms with germline presdiposition or inherited ◯ Myeloproliferative neoplasm (Other than Chronic myeloid leukemia and Hypereosinophilic syndrome) ◯ It covers all "Myeloid Malignancies" disease groups
Disease Group from subnetwork "Myeloid Malignancies" values	_____
Type of educational resource	◯ Onsite/Online training courses ◯ Webinars ◯ Precertorships ◯ Videos ◯ Other
Other - Type of educational resource	_____
Accredited	◯ Yes ◯ No
Accreditation body	_____
Number of credits	_____
Type of credits	◯ Continuing Medical Education (CME) ◯ European Credit Transfer System (ECTS) ◯ Other
Other - Type of credits	_____
What kind of evidence can you provide?	◯ Link ◯ Document (upload) ◯ Both
Evidence (Link)	_____
Document (upload)	(Please upload .pdf, .jpg or .png file up to 30MB)
Title	_____
Calculation of Title	_____

Start date	_____ (If dd and/or mm is not available, complete with 07 for mm and 15 for dd)
End date	_____ (If dd and/or mm is not available, complete with 07 for mm and 15 for dd)
Was the ERN-EuroBloodNet's logo present in the material used for the activity?	◯ Yes ◯ No
Target	◯ Healthcare professionals (physicians, nurses, etc) ◯ Patients (patients community, patients advocates, patients organizations) ◯ Public at large ◯ Other
Target values	_____
Other - Target	_____
Number of participants available?	◯ Yes ◯ No
Number of participants	_____
Number of countries of participants available?	◯ Yes ◯ No
Number of countries of participants	_____
Count activity	_____
Count indicator	_____

If you have to enter an additional Training and Education Activity, click the 'Add another Training and Education Activity' button below.

If all activities have been entered, click the 'Submit' button to finalize the entry process for Training and Education Activities.

If you want to remove the information provided in this form, select "No" in the first question "Do you have any Education/Training activities to report?"

Clinical Trials

Instructions
List all Clinical Trials that were active in 2025.

Eligibility criteria for the Continuous Monitoring

- Involve at least 2 ERN-EuroBloodNet HCPs from 2 Member States
- Ongoing or finalized during the reporting period
- Registered in a recognized public repository (e.g. clinicaltrials.gov)

Do you have any Clinical Trials to report?	◯ Yes ◯ No
Please enter the Clinical Trial number: [current-instance]	
HCP Survey	_____
Subnetowork 'Red Blood Cell Defects'	_____
Subnetowork 'Bone Marrow Failure'	_____
Subnetwork 'Hematochromatosis and Other Iron Disorders'	_____
Subnetowork 'Bleeding - Coagulation Disorders'	_____
Subnetwork 'Lymphoid Malignancies'	_____
Subnetwork 'Myeloid Malignancies'	_____
Subnetworks covered	◯ All RHDs ◯ Red Blood Cell Defects ◯ Bone Marrow Failure ◯ Hematochromatosis and Other Iron Disorders ◯ Bleeding - Coagulation Disorders ◯ Lymphoid Malignancies ◯ Myeloid Malignancies
Diseases covered values	_____

Disease Group from subnetwork "Red Blood Cell Defects"	◯ Alpha-thalassemia and related diseases ◯ Autoinmune hemolytic anemia ◯ Beta-thalassemia and related diseases ◯ Hemoglobinopathy (Other than thalassaemia and sickle cell disease) ◯ Hereditary elliptocytosis ◯ Hereditary spherocytosis ◯ Hereditary stomatocytosis ◯ Rare constitutional hemolytic anemia due to a red cell membrane anomaly (Other than Hereditary Spherocytosis, Hereditary elliptocytosis, Hereditary Stomatocytosis) ◯ Rare constitutional hemolytic anemia due to an enzyme disorder (Other than PKD) ◯ Rare constitutional hemolytic anemia due to pyruvate kinase deficiency (PKD) ◯ Sickle cell disease and related diseases ◯ It covers all "Red Blood Cell Defects" disease groups
Disease Group from subnetwork "Red Blood Cell Defects" values	_____
Disease Group from subnetwork "Bone Marrow Failure"	◯ Blackfan-Diamond Anemia ◯ Congenital dyserythropoietic anemia (Other than type II) ◯ Congenital dyserythropoietic anemia type II ◯ Constitutional Megaloblastic Anemia ◯ Dyskeratosis congenita and related disorders ◯ Fanconi Anemia ◯ Idiopathic Aplastic Anemia ◯ Paroxysmal nocturnal hemoglobinuria ◯ Rare constitutional aplastic anemia (Other than BDA, FA, SD) ◯ Red Cell Aplasia ◯ Shwachman-Diamond syndrome ◯ It covers all "Bone Marrow Failure" disease groups
Disease Group from subnetwork "Bone Marrow Failure" values	_____
Disease Group from subnetwork "Hematochromatosis and Other Iron Disorders"	◯ Aceruloplasminemia ◯ Acquired idiopathic sideroblastic anemia ◯ Congenital atransferrinemia ◯ Constitutional sideroblastic anemia (Other than Severe congenital hypochromic anemia with ringed sideroblastic) ◯ Rare hereditary hemochromatosis (Other than Type 1) ◯ HFE related hereditary hemochromatosis (Symptomatic form of hemochromatosis type 1 - OMIM 235201) ◯ IRIDA syndrome ◯ Microcytic anemia with liver iron overload ◯ Porphyria ◯ Rare Adquired deficiency anemia (Plummer - Vinson syndrome) ◯ Severe congenital hypochromic anemia with ringed sideroblasts ◯ It covers all "Hematochromatosis and Other Iron Disorders" disease groups
Disease Group from subnetwork "Hematochromatosis and Other Iron Disorders" values	_____

Disease Group from subnetwork "Bleeding - Coagulation Disorders"	◯ Atypical hemolytic-uremic syndrome ◯ Hemophilia A ◯ Hemophilia B ◯ Rare hemorrhagic disease due to coagulation factors defects (Other than Hemophilia and VWD) ◯ Rare hemorrhagic disorder due to a constitutional platelet anomaly ◯ Rare hemorrhagic disorder due to an acquired platelet anomaly ◯ Rare thrombotic disorder due to a coagulation factors defect ◯ Rare thrombotic disorder due to quantitative platelet anomaly (High) ◯ Rare thrombotic disorders due to a quantitative platelet anomaly (Low) ◯ Typical hemolytic-uremic syndrome ◯ Von Willebrand Disease ◯ It covers all "Bleeding - Coagulation Disorders" disease groups
Disease Group from subnetwork "Bleeding - Coagulation Disorders" values	_____
Disease Group from subnetwork "Lymphoid Malignancies"	◯ Acute lymphoblastic leukemia ◯ AL amyloidosis ◯ Castleman disease ◯ Dendritic cell neoplasm ◯ Diffuse large B-cell lymphoma, NOS ◯ Diffuse large B-cell lymphoma, other than NOS ◯ Follicular lymphoma ◯ Hairy cell leukemia ◯ Hodgkin Lymphoma ◯ Indolent B-cell lymphomas / Non-follicular ◯ Mantle cell lymphoma ◯ Mature T-cell neoplasm non-primary cutaneous.1 Leukemic ◯ Mature T-cell neoplasm non-primary cutaneous.2 Extra nodal ◯ Mature T-cell neoplasm non-primary cutaneous.2 Nodal ◯ Mature T-cell neoplasms primary cutaneous ◯ Other agressive B-cell neoplasm ◯ Plasma cell neoplasm ◯ Posttransplant lymphoproliferative disorders (PTLD) ◯ It covers all "Lymphoid Malignancies" disease groups
Disease Group from subnetwork "Lymphoid Malignancies" values	_____

Disease Group from subnetwork "Myeloid Malignancies"	◯ Acute myeloid leukemia ◯ Acute promyelocitic leukemia ◯ Chronic myeloid leukemia ◯ Hypereosinophilic syndrome ◯ Mastocytosis ◯ Myelodysplastic syndrome ◯ Myelodysplastic/myeloproliferative disease ◯ Myeloid neoplasms associated with eosinophilia and abnormality of PDGFRA, PDGFRB or FGFR1 ◯ Myeloid neoplasms with germline presdiposition or inherited ◯ Myeloproliferative neoplasm (Other than Chronic myeloid leukemia and Hypereosinophilic syndrome) ◯ It covers all "Myeloid Malignancies" disease groups
Disease Group from subnetwork "Myeloid Malignancies" values	_____
Complete official Title	_____
Calculation Title	_____
Start year	_____
Has the clinical trial ended?	◯ Yes ◯ No
End year	_____
Please check that the end date is before start year.	
The value you provided is out of the reporting period range (2025), please check again. If the Clinical Trial was closed before (2025) then it should not be reported this year.	
Public repository	◯ Clinicaltrials.gov ◯ Other
Other - Public repository	_____
ID (e.g. NCT06250595)	_____
Please check the ID format. Expected NCT + eight digits.	
At least 2 ERN-EuroBloodNet Members/APs from 2 Member States	◯ Yes ◯ No

Members/APs

- ◯ 251 Hellenic Air Force & VA General Hospital
- ◯ Aarhus University Hospital
- ◯ Academic Medical Center Amsterdam
- ◯ Aghia Sophia Children's Hospital
- ◯ AO Padua
- ◯ AORN A Cardarelli
- ◯ AOU - University Luigi Vanvitelli
- ◯ AOU Careggi, Florence
- ◯ AOU Città della Salute e della Scienza di Torino
- ◯ AOU Consorziale polyclinic - Bari
- ◯ AOU Federico II - Naples
- ◯ AOU Modena
- ◯ AOU Ospedali Riuniti "Umberto I - G.M. Lancisi-G. Salesi"
- ◯ AOU Policlinico Umberto I - Rome
- ◯ AOU S.Luigi Gonzaga
- ◯ AOU Siena
- ◯ AOUI Verona
- ◯ Archbishop Makarios III Hospital
- ◯ Assistance Publique-Hôpitaux de Marseille
- ◯ Assistance Publique-Hôpitaux de Paris, Hôpital Henri-Mondor
- ◯ Assistance Publique-Hôpitaux de Paris, Hôpital Necker-Enfants Malades
- ◯ Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Antoine
- ◯ Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis
- ◯ ASST Sette Laghi - Ospedale di Circolo, Varese
- ◯ AUSL Romagna- Presidio Ospedaliero di Ravenna
- ◯ AUSL-IRCCS di Reggio Emilia
- ◯ Azienda Ospedaliero-Universitaria di Parma
- ◯ Azienda Ospedaliero-Universitaria S. Anna di Ferrara
- ◯ Centre Hospitalier du Luxembourg
- ◯ Unidade Local de Saúde de Coimbra (ULS de Coimbra)
- ◯ Centro Hospitalar Universitário de Santo António
- ◯ Charité Universitätsmedizin Berlin
- ◯ Children's Health Ireland
- ◯ CHU de Lille
- ◯ CHU de Limoges
- ◯ CHU de Montpellier
- ◯ CHU de Pointe-à-Pitre/Abymes
- ◯ Copenhagen University Hospital - Rigshospitalet
- ◯ CUB-Hôpital Erasme
- ◯ Erasmus MC: University Medical Center Rotterdam
- ◯ Expert Center on coagolopathias and Congenital Anemias
- ◯ Faculty Hospital of Palacky University Olomouc
- ◯ Foundation CNR Tuscany Region G. Monasterio
- ◯ Foundation IRCCS CA'Granda Ospedale Maggiore polyclinic - Milan
- ◯ Foundation IRCCS Polyclinic San Matteo, Pavia
- ◯ Foundation polyclinic University A. Gemelli - Rome
- ◯ Gemeinschaftsklinikum Mittelrhein gGmbH
- ◯ General Hospital of Athens "LAIKO"
- ◯ Hospices Civils de Lyon
- ◯ Hospital de Sant Joan de Déu- Hospital de la Santa Creu i Sant Pau
- ◯ Hospital General Gregorio Marañón
- ◯ Hospital Universitari Vall d'Hebron
- ◯ Hospital Universitario Virgen del Rocío
- ◯ HUS Helsinki University Hospital, Hospital District of Helsinki and Uusimaa
- ◯ Institut Curie
- ◯ Institute of Hematology and Blood Transfusion, Prague
- ◯ IRCCS Azienda Ospedaliero-Universitaria di Bologna
- ◯ IRCCS Clinical Institute Humanitas - Rozzano
- ◯ IRCCS Institute Giannina Gaslini - Genoa

- ◯ IRCCS Ospedale Pediatrico Bambino Gesù, Roma
- ◯ IRCCS Ospedale San Raffaele di Milano
- ◯ Istituto Scientifico Romagnolo per lo Studio e la Cura dei Tumori (IRST) s.r.l. IRCCS
- ◯ Jules Bordet Institute
- ◯ Karolinska University Hospital
- ◯ Leiden University Medical Center
- ◯ Maria Sklodowska-Curie National Research Institute of Oncology
- ◯ Mater Dei Hospital
- ◯ Medical Faculty Comenius University and Slovak Medical University
- ◯ Medical University of Vienna
- ◯ Ordensklinikum Linz Elisabethinen
- ◯ Ospedale Papa Giovanni XXIII di Bergamo
- ◯ Radboud University Medical Center Nijmegen
- ◯ Riuniti hospitals Villa Sofia-Cervello - Palermo
- ◯ Fondazione IRCCS San Gerardo dei Tintori
- ◯ San Bortolo Hospital - Vicenza
- ◯ Spedali Civili di Brescia
- ◯ Tartu University Hospital
- ◯ Ulm University Medical Center (UUMC)
- ◯ Universitair Ziekenhuis Antwerpen
- ◯ Universitätsklinikum Carl Gustav Carus
- ◯ Universitätsklinikum Freiburg
- ◯ Universitätsklinikum Hamburg-Eppendorf
- ◯ Universitätsklinikum Heidelberg
- ◯ Universitätsklinikum Leipzig
- ◯ Universitätsklinikum Würzburg
- ◯ University Clinical Centre Gdansk
- ◯ University General Hospital Attikon
- ◯ University Hospital Brno
- ◯ University Hospital Leuven
- ◯ University Hospital Liège
- ◯ University Hospital RWTH Aachen
- ◯ University Hospitals Saint-Luc
- ◯ University Medical Center Ljubljana
- ◯ University Medical Center Utrecht
- ◯ University of Debrecen
- ◯ Varna Expert Center of coagulopathies and rare anemias
- ◯ Vilnius University Hospital Santaros Klinikos
- ◯ I do not know

Members/APs values

_____

At least 2 ERN-EuroBloodNet Members/APs should be entered.

Count activity

_____

Count indicator

_____

If you have to enter an additional Clinical Trial, click the 'Add another Clinical Trial' button below.

If all Clinical Trials have been entered, click the 'Submit' button to finalize the entry process for Clinical Trials.

If you want to remove the information provided in this form, select "No" in the first question "Do you have any Clinical Trials to report?"

Observational Studies

Instructions

List all observational studies that were active in 2025. Please fill in all the fields that are marked as mandatory.

Eligibility criteria for the Continuous Monitoring

- Involve at least 2 ERN-EuroBloodNet HCPs from 2 Member States
- Ongoing or finalized during the reporting period
- Registered in a recognized public repository (e.g. clinicaltrials.gov)

Acknowledging ERN-EuroBloodNet

Do you have any Observational Studies to report?

◯ Yes
◯ No

Please enter the Observational study number: [current-instance]

HCP Survey

_____

Subnetwork 'Red Blood Cell Defects'

_____

Subnetwork 'Bone Marrow Failure'

_____

Subnetwork 'Hematochromatosis and Other Iron Disorders'

_____

Subnetwork 'Bleeding - Coagulation Disorders'

_____

Subnetwork 'Lymphoid Malignancies'

_____

Subnetwork 'Myeloid Malignancies'

_____

Subnetworks covered

◯ All RHDs
◯ Red Blood Cell Defects
◯ Bone Marrow Failure
◯ Hematochromatosis and Other Iron Disorders
◯ Bleeding - Coagulation Disorders
◯ Lymphoid Malignancies
◯ Myeloid Malignancies

Diseases covered values

_____

Disease Group from subnetwork "Red Blood Cell Defects"	◯ Alpha-thalassemia and related diseases ◯ Autoinmune hemolytic anemia ◯ Beta-thalassemia and related diseases ◯ Hemoglobinopathy (Other than thalassaemia and sickle cell disease) ◯ Hereditary elliptocytosis ◯ Hereditary spherocytosis ◯ Hereditary stomatocytosis ◯ Rare constitutional hemolytic anemia due to a red cell membrane anomaly (Other than Hereditary Spherocytosis, Hereditary elliptocytosis, Hereditary Stomatocytosis) ◯ Rare constitutional hemolytic anemia due to an enzyme disorder (Other than PKD) ◯ Rare constitutional hemolytic anemia due to pyruvate kinase deficiency (PKD) ◯ Sickle cell disease and related diseases ◯ It covers all "Red Blood Cell Defects" disease groups
Disease Group from subnetwork "Red Blood Cell Defects" values	_____
Disease Group from subnetwork "Bone Marrow Failure"	◯ Blackfan-Diamond Anemia ◯ Congenital dyserythropoietic anemia (Other than type II) ◯ Congenital dyserythropoietic anemia type II ◯ Constitutional Megaloblastic Anemia ◯ Dyskeratosis congenita and related disorders ◯ Fanconi Anemia ◯ Idiopathic Aplastic Anemia ◯ Paroxysmal nocturnal hemoglobinuria ◯ Rare constitutional aplastic anemia (Other than BDA, FA, SD) ◯ Red Cell Aplasia ◯ Shwachman-Diamond syndrome ◯ It covers all "Bone Marrow Failure" disease groups
Disease Group from subnetwork "Bone Marrow Failure" values	_____
Disease Group from subnetwork "Hematochromatosis and Other Iron Disorders"	◯ Aceruloplasminemia ◯ Acquired idiopathic sideroblastic anemia ◯ Congenital atransferrinemia ◯ Constitutional sideroblastic anemia (Other than Severe congenital hypochromic anemia with ringed sideroblastic) ◯ Rare hereditary hemochromatosis (Other than Type 1) ◯ HFE related hereditary hemochromatosis (Symptomatic form of hemochromatosis type 1 - OMIM 235201) ◯ IRIDA syndrome ◯ Microcytic anemia with liver iron overload ◯ Porphyria ◯ Rare Adquired deficiency anemia (Plummer - Vinson syndrome) ◯ Severe congenital hypochromic anemia with ringed sideroblasts ◯ It covers all "Hematochromatosis and Other Iron Disorders" disease groups
Disease Group from subnetwork "Hematochromatosis and Other Iron Disorders"	_____

Disease Group from subnetwork "Bleeding - Coagulation Disorders"	◯ Atypical hemolytic-uremic syndrome ◯ Hemophilia A ◯ Hemophilia B ◯ Rare hemorrhagic disease due to coagulation factors defects (Other than Hemophilia and VWD) ◯ Rare hemorrhagic disorder due to a constitutional platelet anomaly ◯ Rare hemorrhagic disorder due to an acquired platelet anomaly ◯ Rare thrombotic disorder due to a coagulation factors defect ◯ Rare thrombotic disorder due to quantitative platelet anomaly (High) ◯ Rare thrombotic disorders due to a quantitative platelet anomaly (Low) ◯ Typical hemolytic-uremic syndrome ◯ Von Willebrand Disease ◯ It covers all "Bleeding - Coagulation Disorders" disease groups
Disease Group from subnetwork "Bleeding - Coagulation Disorders" values	_____
Disease Group from subnetwork "Lymphoid Malignancies"	◯ Acute lymphoblastic leukemia ◯ AL amyloidosis ◯ Castleman disease ◯ Dendritic cell neoplasm ◯ Diffuse large B-cell lymphoma, NOS ◯ Diffuse large B-cell lymphoma, other than NOS ◯ Follicular lymphoma ◯ Hairy cell leukemia ◯ Hodgkin Lymphoma ◯ Indolent B-cell lymphomas / Non-follicular ◯ Mantle cell lymphoma ◯ Mature T-cell neoplasm non-primary cutaneous.1 Leukemic ◯ Mature T-cell neoplasm non-primary cutaneous.2 Extra nodal ◯ Mature T-cell neoplasm non-primary cutaneous.2 Nodal ◯ Mature T-cell neoplasms primary cutaneous ◯ Other agressive B-cell neoplasm ◯ Plasma cell neoplasm ◯ Posttransplant lymphoproliferative disorders (PTLD) ◯ It covers all "Lymphoid Malignancies" disease groups
Disease Group from subnetwork "Lymphoid Malignancies" values	_____

Disease Group from subnetwork "Myeloid Malignancies"	◯ Acute myeloid leukemia ◯ Acute promyelocitic leukemia ◯ Chronic myeloid leukemia ◯ Hypereosinophilic syndrome ◯ Mastocytosis ◯ Myelodysplastic syndrome ◯ Myelodysplastic/myeloproliferative disease ◯ Myeloid neoplasms associated with eosinophilia and abnormality of PDGFRA, PDGFRB or FGFR1 ◯ Myeloid neoplasms with germline presdiposition or inherited ◯ Myeloproliferative neoplasm (Other than Chronic myeloid leukemia and Hypereosinophilic syndrome) ◯ It covers all "Myeloid Malignancies" disease groups
Disease Group from subnetwork "Myeloid Malignancies"	_____
Complete official Title	_____
Calculation Title	_____
Start year	_____
Has the observational study ended?	◯ Yes ◯ No
End year	_____
Please check that the end date is before start year.	
The value you provided is out of the reporting period range (2025), please check again. If the Observational Study was closed before (2025) then it should not be reported this year.	
Public repository	◯ Clinicaltrials.gov ◯ Other
Other - Public repository	_____
ID (e.g. NCT06250595)	_____
Please check the ID format. Expected NCT + eight digits.	
At least 2 ERN-EuroBloodNet Members/APs from 2 Member States	◯ Yes ◯ No

Members/APs

- ◯ Ospedale Papa Giovanni XXIII di Bergamo
- ◯ 251 Hellenic Air Force & VA General Hospital
- ◯ Aarhus University Hospital
- ◯ Academic Medical Center Amsterdam
- ◯ Aghia Sophia Children's Hospital
- ◯ AO Padua
- ◯ AORN A Cardarelli
- ◯ AOU - University Luigi Vanvitelli
- ◯ AOU Careggi, Florence
- ◯ AOU Città della Salute e della Scienza di Torino
- ◯ AOU Consorziale polyclinic - Bari
- ◯ AOU Federico II - Naples
- ◯ AOU Modena
- ◯ AOU Ospedali Riuniti "Umberto I - G.M. Lancisi-G. Salesi"
- ◯ AOU Policlinico Umberto I - Rome
- ◯ AOU S.Luigi Gonzaga
- ◯ AOU Siena
- ◯ AOUI Verona
- ◯ Archbishop Makarios III Hospital
- ◯ Assistance Publique-Hôpitaux de Marseille
- ◯ Assistance Publique-Hôpitaux de Paris, Hôpital Henri-Mondor
- ◯ Assistance Publique-Hôpitaux de Paris, Hôpital Necker-Enfants Malades
- ◯ Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Antoine
- ◯ Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis
- ◯ ASST Sette Laghi - Ospedale di Circolo, Varese
- ◯ AUSL Romagna- Presidio Ospedaliero di Ravenna
- ◯ AUSL-IRCCS di Reggio Emilia
- ◯ Azienda Ospedaliero-Universitaria di Parma
- ◯ Azienda Ospedaliero-Universitaria S. Anna di Ferrara
- ◯ Centre Hospitalier du Luxembourg
- ◯ Centro Hospitalar e Universitário de Coimbra, EPE
- ◯ Centro Hospitalar Universitário de Santo António
- ◯ Charité Universitätsmedizin Berlin
- ◯ Children's Health Ireland
- ◯ CHU de Lille
- ◯ CHU de Limoges
- ◯ CHU de Montpellier
- ◯ CHU de Pointe-à-Pitre/Abymes
- ◯ Copenhagen University Hospital - Rigshospitalet
- ◯ CUB-Hôpital Erasme
- ◯ Erasmus MC: University Medical Center Rotterdam
- ◯ Expert Center on coagolopathias and Congenital Anemias
- ◯ Faculty Hospital of Palacky University Olomouc
- ◯ Fondazione IRCCS San Gerardo dei Tintori
- ◯ Foundation CNR Tuscany Region G. Monasterio
- ◯ Foundation IRCCS CA'Granda Ospedale Maggiore polyclinic - Milan
- ◯ Foundation IRCCS Polyclinic San Matteo, Pavia
- ◯ Foundation polyclinic University A. Gemelli - Rome
- ◯ Gemeinschaftsklinikum Mittelrhein gGmbH
- ◯ General Hospital of Athens "LAIKO"
- ◯ Hospices Civils de Lyon
- ◯ Hospital de Sant Joan de Déu- Hospital de la Santa Creu i Sant Pau
- ◯ Hospital General Gregorio Marañón
- ◯ Hospital Universitari Vall d'Hebron
- ◯ Hospital Universitario Virgen del Rocío
- ◯ HUS Helsinki University Hospital, Hospital District of Helsinki and Uusimaa
- ◯ Institut Curie
- ◯ Institute of Hematology and Blood Transfusion, Prague
- ◯ IRCCS Azienda Ospedaliero-Universitaria di Bologna

◯ IRCCS Clinical Institute Humanitas - Rozzano
◯ IRCCS Institute Giannina Gaslini - Genoa
◯ IRCCS Ospedale Pediatrico Bambino Gesù, Roma
◯ IRCCS Ospedale San Raffaele di Milano
◯ Istituto Scientifico Romagnolo per lo Studio e la Cura dei Tumori (IRST) s.r.l. IRCCS
◯ Jules Bordet Institute
◯ Karolinska University Hospital
◯ Leiden University Medical Center
◯ Maria Sklodowska-Curie National Research Institute of Oncology
◯ Mater Dei Hospital
◯ Medical Faculty Comenius University and Slovak Medical University
◯ Medical University of Vienna
◯ Ordensklinikum Linz Elisabethinen
◯ Radboud University Medical Center Nijmegen
◯ Riuniti hospitals Villa Sofia-Cervello - Palermo
◯ San Bortolo Hospital - Vicenza
◯ Spedali Civili di Brescia
◯ Tartu University Hospital
◯ Ulm University Medical Center (UUMC)
◯ Universitair Ziekenhuis Antwerpen
◯ Universitätsklinikum Carl Gustav Carus
◯ Universitätsklinikum Freiburg
◯ Universitätsklinikum Hamburg-Eppendorf
◯ Universitätsklinikum Heidelberg
◯ Universitätsklinikum Leipzig
◯ Universitätsklinikum Würzburg
◯ University Clinical Centre
◯ University General Hospital Attikon
◯ University Hospital Brno
◯ University Hospital Leuven
◯ University Hospital Liège
◯ University Hospital RWTH Aachen
◯ University Hospitals Saint-Luc
◯ University Medical Center Ljubljana
◯ University Medical Center Utrecht
◯ University of Debrecen
◯ Varna Expert Center of coagulopathies and rare anemias
◯ Vilnius University Hospital Santaros Klinikos

Members/APs values

_____

At least 2 ERN-EuroBloodNet Members/APs should be entered.

Acknowledgement

◯ Yes
◯ No

Count activity

_____

Count indicator

_____

If you have to enter an additional Observational Study, click the 'Add another Observational Study' button below.

If all Observational Studies have been entered, click the 'Submit' button to finalize the entry process for Observational Studies.

If you want to remove the information provided in this form, select "No" in the first question "Do you have any Observational Studies to report?"

Publications

Instructions

Accepted peer-reviewed publications in scientific journals in 2025.

Eligibility criteria for the Continuous Monitoring

- Involve at least 2 ERN-EuroBloodNet HCPs from 2 Member States
- Published in PubMed

Acknowledging ERN-EuroBloodNet

Do you have any Publications to report?	◯ Yes ◯ No
Please enter the Publication activity number: [current-instance]	
HCP Survey	_____
Subnetowork 'Red Blood Cell Defects'	_____
Subnetwork 'Bone Marrow Failure'	_____
Subnetowork 'Hematochromatosis and Other Iron Disorders'	_____
Subnetowork 'Bleeding - Coagulation Disorders'	_____
Subnetowork 'Lymphoid Malignancies'	_____
Subnetowork 'Myeloid Malignancies'	_____
Subnetworks covered	◯ All RHDs ◯ Red Blood Cell Defects ◯ Bone Marrow Failure ◯ Hematochromatosis and Other Iron Disorders ◯ Bleeding - Coagulation Disorders ◯ Lymphoid Malignancies ◯ Myeloid Malignancies
Diseases covered values	_____

Disease Group from subnetwork "Red Blood Cell Defects"	◯ Alpha-thalassemia and related diseases ◯ Autoinmune hemolytic anemia ◯ Beta-thalassemia and related diseases ◯ Hemoglobinopathy (Other than thalassaemia and sickle cell disease) ◯ Hereditary elliptocytosis ◯ Hereditary spherocytosis ◯ Hereditary stomatocytosis ◯ Rare constitutional hemolytic anemia due to a red cell membrane anomaly (Other than Hereditary Spherocytosis, Hereditary elliptocytosis, Hereditary Stomatocytosis) ◯ Rare constitutional hemolytic anemia due to an enzyme disorder (Other than PKD) ◯ Rare constitutional hemolytic anemia due to pyruvate kinase deficiency (PKD) ◯ Sickle cell disease and related diseases ◯ It covers all "Red Blood Cell Defects" disease groups
Disease Group from subnetwork "Red Blood Cell Defects" values	_____
Disease Group from subnetwork "Bone Marrow Failure"	◯ Blackfan-Diamond Anemia ◯ Congenital dyserythropoietic anemia (Other than type II) ◯ Congenital dyserythropoietic anemia type II ◯ Constitutional Megaloblastic Anemia ◯ Dyskeratosis congenita and related disorders ◯ Fanconi Anemia ◯ Idiopathic Aplastic Anemia ◯ Paroxysmal nocturnal hemoglobinuria ◯ Rare constitutional aplastic anemia (Other than BDA, FA, SD) ◯ Red Cell Aplasia ◯ Shwachman-Diamond syndrome ◯ It covers all "Bone Marrow Failure" disease groups
Disease Group from subnetwork "Bone Marrow Failure" values	_____
Disease Group from subnetwork "Hematochromatosis and Other Iron Disorders"	◯ Aceruloplasminemia ◯ Acquired idiopathic sideroblastic anemia ◯ Congenital atransferrinemia ◯ Constitutional sideroblastic anemia (Other than Severe congenital hypochromic anemia with ringed sideroblastic) ◯ Rare hereditary hemochromatosis (Other than Type 1) ◯ HFE related hereditary hemochromatosis (Symptomatic form of hemochromatosis type 1 - OMIM 235201) ◯ IRIDA syndrome ◯ Microcytic anemia with liver iron overload ◯ Porphyria ◯ Rare Adquired deficiency anemia (Plummer - Vinson syndrome) ◯ Severe congenital hypochromic anemia with ringed sideroblasts ◯ It covers all "Hematochromatosis and Other Iron Disorders" disease groups
Disease Group from subnetwork "Hematochromatosis and Other Iron Disorders" values	_____

Disease Group from subnetwork "Bleeding - Coagulation Disorders"	◯ Atypical hemolytic-uremic syndrome ◯ Hemophilia A ◯ Hemophilia B ◯ Rare hemorrhagic disease due to coagulation factors defects (Other than Hemophilia and VWD) ◯ Rare hemorrhagic disorder due to a constitutional platelet anomaly ◯ Rare hemorrhagic disorder due to an acquired platelet anomaly ◯ Rare thrombotic disorder due to a coagulation factors defect ◯ Rare thrombotic disorder due to quantitative platelet anomaly (High) ◯ Rare thrombotic disorders due to a quantitative platelet anomaly (Low) ◯ Typical hemolytic-uremic syndrome ◯ Von Willebrand Disease ◯ It covers all "Bleeding - Coagulation Disorders" disease groups
Disease Group from subnetwork "Bleeding - Coagulation Disorders" values	_____
Disease Group from subnetwork "Lymphoid Malignancies"	◯ Acute lymphoblastic leukemia ◯ AL amyloidosis ◯ Castleman disease ◯ Dendritic cell neoplasm ◯ Diffuse large B-cell lymphoma, NOS ◯ Diffuse large B-cell lymphoma, other than NOS ◯ Follicular lymphoma ◯ Hairy cell leukemia ◯ Hodgkin Lymphoma ◯ Indolent B-cell lymphomas / Non-follicular ◯ Mantle cell lymphoma ◯ Mature T-cell neoplasm non-primary cutaneous.1 Leukemic ◯ Mature T-cell neoplasm non-primary cutaneous.2 Extra nodal ◯ Mature T-cell neoplasm non-primary cutaneous.2 Nodal ◯ Mature T-cell neoplasms primary cutaneous ◯ Other agressive B-cell neoplasm ◯ Plasma cell neoplasm ◯ Posttransplant lymphoproliferative disorders (PTLD) ◯ It covers all "Lymphoid Malignancies" disease groups
Disease Group from subnetwork "Lymphoid Malignancies"	_____

Disease Group from subnetwork "Myeloid Malignancies"	◯ Acute myeloid leukemia ◯ Acute promyelocitic leukemia ◯ Chronic myeloid leukemia ◯ Hypereosinophilic syndrome ◯ Mastocytosis ◯ Myelodysplastic syndrome ◯ Myelodysplastic/myeloproliferative disease ◯ Myeloid neoplasms associated with eosinophilia and abnormality of PDGFRA, PDGFRB or FGFR1 ◯ Myeloid neoplasms with germline presdiposition or inherited ◯ Myeloproliferative neoplasm (Other than Chronic myeloid leukemia and Hypereosinophilic syndrome) ◯ It covers all "Myeloid Malignancies" disease groups
Disease Group from subnetwork "Myeloid Malignancies" values	_____
Title	_____
Calculation Title	_____
Publication date	_____ (If dd and/or mm is not available, complete with 07 for mm and 15 for dd)
Pubmed DOI Code (e.g.10.1002/pbc.31190)	_____
Please insert a link	_____
At least 2 ERN-EuroBloodNet Members/APs from 2 Member States	◯ Yes ◯ No

Members/APs

- ◯ Ospedale Papa Giovanni XXIII di Bergamo
- ◯ 251 Hellenic Air Force & VA General Hospital
- ◯ Aarhus University Hospital
- ◯ Academic Medical Center Amsterdam
- ◯ Aghia Sophia Children's Hospital
- ◯ AO Padua
- ◯ AORN A Cardarelli
- ◯ AOU - University Luigi Vanvitelli
- ◯ AOU Careggi, Florence
- ◯ AOU Città della Salute e della Scienza di Torino
- ◯ AOU Consorziale polyclinic - Bari
- ◯ AOU Federico II - Naples
- ◯ AOU Modena
- ◯ AOU Ospedali Riuniti "Umberto I - G.M. Lancisi-G. Salesi"
- ◯ AOU Policlinico Umberto I - Rome
- ◯ AOU S.Luigi Gonzaga
- ◯ AOU Siena
- ◯ AOUI Verona
- ◯ Archbishop Makarios III Hospital
- ◯ Assistance Publique-Hôpitaux de Marseille
- ◯ Assistance Publique-Hôpitaux de Paris, Hôpital Henri-Mondor
- ◯ Assistance Publique-Hôpitaux de Paris, Hôpital Necker-Enfants Malades
- ◯ Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Antoine
- ◯ Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis
- ◯ ASST Sette Laghi - Ospedale di Circolo, Varese
- ◯ AUSL Romagna- Presidio Ospedaliero di Ravenna
- ◯ AUSL-IRCCS di Reggio Emilia
- ◯ Azienda Ospedaliero-Universitaria di Parma
- ◯ Azienda Ospedaliero-Universitaria S. Anna di Ferrara
- ◯ Centre Hospitalier du Luxembourg
- ◯ Centro Hospitalar e Universitário de Coimbra, EPE
- ◯ Centro Hospitalar Universitário de Santo António
- ◯ Charité Universitätsmedizin Berlin
- ◯ Children's Health Ireland
- ◯ CHU de Lille
- ◯ CHU de Limoges
- ◯ CHU de Montpellier
- ◯ CHU de Pointe-à-Pitre/Abymes
- ◯ Copenhagen University Hospital - Rigshospitalet
- ◯ CUB-Hôpital Erasme
- ◯ Erasmus MC: University Medical Center Rotterdam
- ◯ Expert Center on coagolopathias and Congenital Anemias
- ◯ Faculty Hospital of Palacky University Olomouc
- ◯ Fondazione IRCCS San Gerardo dei Tintori
- ◯ Foundation CNR Tuscany Region G. Monasterio
- ◯ Foundation IRCCS CA'Granda Ospedale Maggiore polyclinic - Milan
- ◯ Foundation IRCCS Polyclinic San Matteo, Pavia
- ◯ Foundation polyclinic University A. Gemelli - Rome
- ◯ Gemeinschaftsklinikum Mittelrhein gGmbH
- ◯ General Hospital of Athens "LAIKO"
- ◯ Hospices Civils de Lyon
- ◯ Hospital de Sant Joan de Déu- Hospital de la Santa Creu i Sant Pau
- ◯ Hospital General Gregorio Marañón
- ◯ Hospital Universitari Vall d'Hebron
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◯ Mater Dei Hospital
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◯ Medical University of Vienna
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◯ Spedali Civili di Brescia
◯ Tartu University Hospital
◯ Ulm University Medical Center (UUMC)
◯ Universitair Ziekenhuis Antwerpen
◯ Universitätsklinikum Carl Gustav Carus
◯ Universitätsklinikum Freiburg
◯ Universitätsklinikum Hamburg-Eppendorf
◯ Universitätsklinikum Heidelberg
◯ Universitätsklinikum Leipzig
◯ Universitätsklinikum Würzburg
◯ University Clinical Centre
◯ University General Hospital Attikon
◯ University Hospital Brno
◯ University Hospital Leuven
◯ University Hospital Liège
◯ University Hospital RWTH Aachen
◯ University Hospitals Saint-Luc
◯ University Medical Center Ljubljana
◯ University Medical Center Utrecht
◯ University of Debrecen
◯ Varna Expert Center of coagulopathies and rare anemias
◯ Vilnius University Hospital Santaros Klinikos

Members/APs values

_____

At least 2 ERN-EuroBloodNet Members/APs should be entered.

Acknowledgement

◯ Yes
◯ No

Count activity

_____

Count indicator

_____

If you have to enter an additional Publication, click the 'Add another Publication' button below.

If all Publications have been entered, click the 'Submit' button to finalize the entry process for Publications.

If you want to remove the information provided in this form, select "No" in the first question "Do you have any Publications to report?"

Communication and Dissemination

Instructions

List all Congresses/Conferences/Meetings at which the ERN-EuroBloodNet activities and results were presented in 2025.

Eligibility criteria for the Continuous Monitoring

- ERN-EuroBloodNet and its activities must be the focus of the presentation, and must be reflected in the programme/agenda
- ERN-EuroBloodNet logo must be present in the Evidence
- Materials should be made public and available

Do you have any Congresses/Conferences/Meetings to report?	◯ Yes ◯ No
Please enter the Communication and Dissemination activity number: [current-instance]	
HCP Survey	_____
Subnetowork 'Red Blood Cell Defects'	_____
Subnetowork 'Bone Marrow Failure'	_____
Subnetowork 'Hematochromatosis and Other Iron Disorders'	_____
Subnetowork 'Bleeding - Coagulation Disorders'	_____
Subnetowork 'Lymphoid Malignancies'	_____
Subnetowork 'Myeloid Malignancies'	_____
Subnetworks covered	◯ All RHDs ◯ Red Blood Cell Defects ◯ Bone Marrow Failure ◯ Hematochromatosis and Other Iron Disorders ◯ Bleeding - Coagulation Disorders ◯ Lymphoid Malignancies ◯ Myeloid Malignancies
Diseases covered	_____

Disease Group from subnetwork "Red Blood Cell Defects"	◯ Alpha-thalassemia and related diseases ◯ Autoinmune hemolytic anemia ◯ Beta-thalassemia and related diseases ◯ Hemoglobinopathy (Other than thalassaemia and sickle cell disease) ◯ Hereditary elliptocytosis ◯ Hereditary spherocytosis ◯ Hereditary stomatocytosis ◯ Rare constitutional hemolytic anemia due to a red cell membrane anomaly (Other than Hereditary Spherocytosis, Hereditary elliptocytosis, Hereditary Stomatocytosis) ◯ Rare constitutional hemolytic anemia due to an enzyme disorder (Other than PKD) ◯ Rare constitutional hemolytic anemia due to pyruvate kinase deficiency (PKD) ◯ Sickle cell disease and related diseases ◯ It covers all "Red Blood Cell Defects" disease groups
Disease Group from subnetwork "Red Blood Cell Defects" values	_____
Disease Group from subnetwork "Bone Marrow Failure"	◯ Blackfan-Diamond Anemia ◯ Congenital dyserythropoietic anemia (Other than type II) ◯ Congenital dyserythropoietic anemia type II ◯ Constitutional Megaloblastic Anemia ◯ Dyskeratosis congenita and related disorders ◯ Fanconi Anemia ◯ Idiopathic Aplastic Anemia ◯ Paroxysmal nocturnal hemoglobinuria ◯ Rare constitutional aplastic anemia (Other than BDA, FA, SD) ◯ Red Cell Aplasia ◯ Shwachman-Diamond syndrome ◯ It covers all "Bone Marrow Failure" disease groups
Disease Group from subnetwork "Bone Marrow Failure" values	_____
Disease Group from subnetwork "Hematochromatosis and Other Iron Disorders"	◯ Aceruloplasminemia ◯ Acquired idiopathic sideroblastic anemia ◯ Congenital atransferrinemia ◯ Constitutional sideroblastic anemia (Other than Severe congenital hypochromic anemia with ringed sideroblastic) ◯ Rare hereditary hemochromatosis (Other than Type 1) ◯ HFE related hereditary hemochromatosis (Symptomatic form of hemochromatosis type 1 - OMIM 235201) ◯ IRIDA syndrome ◯ Microcytic anemia with liver iron overload ◯ Porphyria ◯ Rare Adquired deficiency anemia (Plummer - Vinson syndrome) ◯ Severe congenital hypochromic anemia with ringed sideroblasts ◯ It covers all "Hematochromatosis and Other Iron Disorders" disease groups
Disease Group from subnetwork "Hematochromatosis and Other Iron Disorders" values	_____

Disease Group from subnetwork "Bleeding - Coagulation Disorders"	◯ Atypical hemolytic-uremic syndrome ◯ Hemophilia A ◯ Hemophilia B ◯ Rare hemorrhagic disease due to coagulation factors defects (Other than Hemophilia and VWD) ◯ Rare hemorrhagic disorder due to a constitutional platelet anomaly ◯ Rare hemorrhagic disorder due to an acquired platelet anomaly ◯ Rare thrombotic disorder due to a coagulation factors defect ◯ Rare thrombotic disorder due to quantitative platelet anomaly (High) ◯ Rare thrombotic disorders due to a quantitative platelet anomaly (Low) ◯ Typical hemolytic-uremic syndrome ◯ Von Willebrand Disease ◯ It covers all "Bleeding - Coagulation Disorders" disease groups
Disease Group from subnetwork "Bleeding - Coagulation Disorders"	_____
Disease Group from subnetwork "Lymphoid Malignancies"	◯ Acute lymphoblastic leukemia ◯ AL amyloidosis ◯ Castleman disease ◯ Dendritic cell neoplasm ◯ Diffuse large B-cell lymphoma, NOS ◯ Diffuse large B-cell lymphoma, other than NOS ◯ Follicular lymphoma ◯ Hairy cell leukemia ◯ Hodgkin Lymphoma ◯ Indolent B-cell lymphomas / Non-follicular ◯ Mantle cell lymphoma ◯ Mature T-cell neoplasm non-primary cutaneous.1 Leukemic ◯ Mature T-cell neoplasm non-primary cutaneous.2 Extra nodal ◯ Mature T-cell neoplasm non-primary cutaneous.2 Nodal ◯ Mature T-cell neoplasms primary cutaneous ◯ Other agressive B-cell neoplasm ◯ Plasma cell neoplasm ◯ Posttransplant lymphoproliferative disorders (PTLD) ◯ It covers all "Lymphoid Malignancies" disease groups
Disease Group from subnetwork "Lymphoid Malignancies" values	_____

Disease Group from subnetwork "Myeloid Malignancies"	◯ Acute myeloid leukemia ◯ Acute promyelocitic leukemia ◯ Chronic myeloid leukemia ◯ Hypereosinophilic syndrome ◯ Mastocytosis ◯ Myelodysplastic syndrome ◯ Myelodysplastic/myeloproliferative disease ◯ Myeloid neoplasms associated with eosinophilia and abnormality of PDGFRA, PDGFRB or FGFR1 ◯ Myeloid neoplasms with germline presdiposition or inherited ◯ Myeloproliferative neoplasm (Other than Chronic myeloid leukemia and Hypereosinophilic syndrome) ◯ It covers all "Myeloid Malignancies" disease groups
Disease Group from subnetwork "Myeloid Malignancies" values	_____
Title of the Event (Congress...)	_____
Calculation Title of the Event (Congress...)	_____
Start date	_____ (If dd and/or mm is not available, complete with 07 for mm and 15 for dd)
End date	_____ (If dd and/or mm is not available, complete with 07 for mm and 15 for dd)
Title of the Presentation	_____
Evidence (Link)	_____
Was the ERN-EuroBloodNet's logo present in the material used for the activity?	◯ Yes ◯ No
Target	◯ Healthcare professionals (physicians, nurses, etc) ◯ Patients (patients community, patients advocates, patients organizations) ◯ Public at large ◯ Other
Target values	_____
Other - Target	_____
Count activity	_____

Count indicator

If you have to enter an additional Communication and Dissemination activity click the 'Add another Communication and Dissemination activity' button below.

If all Communication and Dissemination activities have been entered, click the 'Submit' button to finalize the entry process for Communication and Dissemination.

If you want to remove the information provided in this form, select "No" in the first question "Do you have any Congresses/Conferences/Meetings to report?"

Clinical Practice Guidelines (CPGs) and Clinical Decision-Making Tools (CDMTs)

Instructions

- Choose the CPGs and CDMTs endorsed by ERN-EuroBloodNet implemented in your HCP.
- Add additional rows for any other relevant international CPGs and CDMTs that are implemented in your HCP

Select the CPG/CDMT adopted as part of your HCP expertise's subnetwork.
(Use Ctrl+F (Windows) or Cmd+F (Mac) to quickly find the guidelines you are looking for)

HCP Survey	
Subnetwork 'Red Blood Cell Defects'	
Subnetwork 'Bone Marrow Failure'	
Subnetwork 'Hematochromatosis and Other Iron Disorders'	
Subnetwork 'Bleeding - Coagulation Disorders'	
Subnetwork 'Lymphoid Malignancies'	
Subnetwork 'Myeloid Malignancies'	

CPG/CDSTs adopted (subnetwork "Red Blood Cell Defects")	☐ A guide for haemoglobinopathy nurse ☐ A Short Guide to the Management of Transfusion Dependent Thalassaemia ☐ Addressing the diagnostic gaps in pyruvate kinase deficiency: Consensus recommendations on the diagnosis of pyruvate kinase deficiency. (2019) ☐ Antenatal Laboratory Handbook SCD Thal ☐ Clinical Pharmacogenetics Implementation Consortium (CPIC) guidelines for rasburicase therapy in the context of G6PD deficiency genotype. ☐ Emergency Management of Thalassaemia (2012) ☐ EMQN Best Practice Guidelines for molecular and haematology methods for carrier identification and prenatal diagnosis of the haemoglobinopathies ☐ ENERCA clinical recommendations for disease management and prevention of complications of sickle cell disease in children ☐ Evidence-Based Management of Sickle Cell Disease: Expert Panel Report, 2014 ☐ Guidelines for the diagnosis and management of hereditary spherocytosis - 2011 update ☐ Guidelines for the diagnosis, investigation and management of polycythaemia/erythrocytosis ☐ Guidelines for the management of non transfusion dependent thalassaemia (NTDT) 2ND edition ☐ Guidelines for the Management of Transfusion Dependent Thalassaemia, 3rd Edition (2014) ☐ Guidelines for the Management of Transfusion-Dependent Thalassaemia (4th Edition - 2021) ☐ ICSH guidelines for the laboratory diagnosis of nonimmune hereditary red cell membrane disorders ☐ International Guidelines for the Diagnosis and Management of Pyruvate Kinase Deficiency ☐ Management of Non-Transfusion-Dependent Thalassemia: A Practical Guide ☐ Newborn screening for sickle cell disease in Europe: recommendations from a Pan-European Consensus Conference ☐ NHS SCT Handbook for Newborn Laboratories ☐ Preterm Neonates: Beyond the Guidelines for Neonatal Hyperbilirubinemia ☐ Prevention and Diagnosis of Haemoglobinopathies: A Short Guide for Health Professionals and Laboratory Scientists (2016) ☐ Prevention of Thalassaemias and other Haemoglobin Disorders, Vol 1, 2nd Edition (2013) ☐ Prevention of Thalassaemias and Other Haemoglobin Disorders, Vol. 2: Laboratory Protocols (2012) ☐ Recommendations for diagnosis and treatment of methemoglobinemia ☐ Recommendations regarding splenectomy in hereditary hemolytic anemias. ☐ Recommended methods for the characterization of red cell pyruvate kinase variants ☐ Significant haemoglobinopathies: guidelines for screening and diagnosis ☐ Standards for the clinical care of children and adults with thalassaemia in the UK ☐ No CPGs-CDMTs adopted for this Subnetwork

CPG/CDSTs adopted (subnetwork "Bone Marrow Failure")	☐ Diagnosing and treating Diamond Blackfan anaemia: results of an international clinical consensus conference ☐ Diagnosis and management of congenital dyserythropoietic anemias ☐ GATA2 deficiency and related myeloid neoplasms ☐ Guidelines for the diagnosis and management of adult aplastic anaemia ☐ Haematopoietic and immune defects associated with GATA2 mutation ☐ How I manage patients with Fanconi anaemia ☐ How I treat Diamond-Blackfan anemia ☐ How I treat MDS and AML in Fanconi anemia ☐ Paroxysmal Nocturnal Hemoglobinuria ☐ Paroxysmal Nocturnal Hemoglobinuria ☐ Recommendations on hematopoietic stem cell transplantation for inherited bone marrow failure syndromes ☐ Recommendations regarding splenectomy in hereditary hemolytic anemias. ☐ Transplantation for bone marrow failure: current issues ☐ No CPGs-CDMTs adopted for this Subnetwork
CPG/CDSTs adopted (subnetwork "Hematochromatosis and Other Iron Disorders")	☐ American Association for the Study of Liver Diseases.Diagnosis and management of hemochromatosis: 2011 practice guideline by the American Association for the Study of Liver Diseases ☐ EMQN best practice guidelines for the molecular genetic diagnosis of hereditary hemochromatosis (HH) ☐ European Association For The Study Of The Liver. EASL clinical practice guidelines for HFE hemochromatosis. ☐ Key-interventions derived from three evidence based guidelines for management and follow-up of patients with HFE haemochromatosis. ☐ Molecular diagnosis of hemochromatosis ☐ Practice guidelines for the diagnosis and management of microcytic anemias due to genetic disorders of iron metabolism or heme synthesis ☐ Reassessing the Safety Concerns of Utilizing Blood Donations from Patients with Hemochromatosis. Hepatology ☐ The quality of hereditary haemochromatosis guidelines: a comparative analysis ☐ Therapeutic recommendations in HFE hemochromatosis for p.Cys282Tyr (C282Y/C282Y) homozygous genotype ☐ No CPGs-CDMTs adopted for this Subnetwork

CPG/CDSTs adopted (subnetwork "Bleeding - Coagulation Disorders")

- ☐ A framework for genetic service provision for haemophilia and other inherited bleeding disorders
- ☐ A review of inherited platelet disorders with guidelines for their management on behalf of the UKHCDO
- ☐ A United Kingdom Haemophilia Centre Doctors' Organization guideline approved by the British Committee for Standards in Haematology: guideline on the use of prophylactic factor VIII concentrate in children and adults with severe haemophilia A
- ☐ Diagnostic and treatment guidelines for thrombotic thrombocytopenic purpura (TTP) 2017 in Japan
- ☐ Emergency and out of hours care for patients with bleeding disorders - Standards of care for assessment and treatment
- ☐ European principles of inhibitor management in patients with haemophilia.
- ☐ Guideline on the diagnosis and management of chronic liver disease in haemophilia
- ☐ Guideline on the management of haemophilia in the fetus and neonate
- ☐ Guideline on the selection and use of therapeutic products to treat haemophilia and other hereditary bleeding disorders. A United Kingdom Haemophilia Center Doctors' Organisation (UKHCDO) guideline approved by the British Committee for Standards in Haematology
- ☐ Guidelines for the management of acute joint bleeds and chronic synovitis in haemophilia: A United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO) guideline.
- ☐ Guidelines on the diagnosis and management of thrombotic thrombocytopenic purpura and other thrombotic microangiopathies.
- ☐ Management of von Willebrand's disease: a guideline from the UK Haemophilia Centre Doctors' Organisation
- ☐ Practice Guidelines for the Molecular Diagnosis of Haemophilia A
- ☐ Practice Guidelines for the Molecular Diagnosis of Haemophilia B
- ☐ Primary prophylaxis in haemophilia care: Guideline update 2016
- ☐ The diagnosis and management of factor VIII and IX inhibitors: a guideline from the United Kingdom Haemophilia Centre Doctors Organisation
- ☐ The diagnosis of von Willebrand's disease: a guideline from the UK Haemophilia Centre Doctors' Organisation
- ☐ The molecular analysis of von Willebrand disease: a guideline from the UK Haemophilia Centre Doctors' Organisation Haemophilia Genetics Laboratory Network
- ☐ The obstetric and gynaecological management of women with inherited bleeding disorders-review with guidelines produced by a taskforce of UK Haemophilia Centre Doctors' Organization
- ☐ The rare coagulation disorders--review with guidelines for management from the United Kingdom Haemophilia Centre Doctors' Organisation
- ☐ UKHCDO guidelines on the management of HCV in patients with hereditary bleeding disorders 2011.
- ☐ WFH Guidelines: Guidelines for the management of haemophilia
- ☐ No CPGs-CDMTs adopted for this Subnetwork

CPG/CDSTs adopted (subnetwork "Lymphoid Malignancies")	☐ A complementary role of multiparameter flow cytometry and high-throughput sequencing for minimal residual disease detection in chronic lymphocytic leukemia: an European Research Initiative on CLL study. ☐ Acute lymphoblastic leukemia in adult patients: ESMO clinical practice guidelines for diagnosis, treatment and follow-up ☐ Acute lymphoblastic leukemia: Version 2.2015 ☐ AL amyloidosis: from molecular mechanisms to targeted therapies ☐ ERIC recommendations for TP53 mutation analysis in chronic lymphocytic leukemia-update on methodological approaches and results interpretation. ☐ ESMO Consensus conferences: guidelines on malignant lymphoma. part 2: marginal zone lymphoma, mantle cell lymphoma, peripheral T-cell lymphoma ☐ ESMO Guidelines consensus conference on malignant lymphoma 2011 part 1: diffuse large B-cell lymphoma (DLBCL), follicular lymphoma (FL) and chronic lymphocytic leukemia (CLL) ☐ Gastric marginal zone lymphoam of MALT type: ESMO clinical practice guidelines for diagnosis, treatment and follow-up ☐ Guideline for the diagnosis, treatment and response criteria for Bing-Neel syndrome ☐ Guidelines for Diagnosis, Indications for Treatment, Response Assessment and Supportive Management of Chronic Lymphocytic Leukemia ☐ Guidelines on the management of AL amyloidosis ☐ Hairy cell leukaemia: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up ☐ High-risk chronic lymphocytic leukemia in the era of pathway inhibitors: integrating molecular and cellular therapies. ☐ Hodgkin lymphoma, Version 1.2017 ☐ Hodgkin´s lymphoma in adults: diagnosis, treatment and follow-up ☐ Hodgkin´s lymphoma: ESMO clinical practice guidelines on diagnosis, treatment and follow up ☐ Immunoglobulin gene sequence analysis in chronic lymphocytic leukemia: updated ERIC recommendations. ☐ Investigation and management of IgM and Waldenström-associated peripheral neuropathies: recommendations from the IWWM-8 consensus panel ☐ Reproducible diagnosis of chronic lymphocytic leukemia by flow cytometry: An European Research Initiative on CLL (ERIC) & European Society for Clinical Cell Analysis (ESCCA) Harmonisation project ☐ Response assessment in Waldenström macroglobulinaemia: update from the VIth International Workshop ☐ Treatment recommendations from the Eighth International Workshop on Waldenström's Macroglobulinemia ☐ Update on nodal and splenic marginal zone lymphoma ☐ No CPGs-CDMTs adopted for this Subnetwork

CPG/CDSTs adopted (subnetwork "Myeloid Malignancies")	☐ Allogeneic hematopoietic stem cell transplantation for MDS and CMML: recommendations from an international expert panel. ☐ An international consortium proposal of uniform response criteria for myelodysplastic/myeloproliferative neoplasms (MDS/MPN) in adults. ☐ Diagnosis and management of AML in adults: 2017 ELN recommendations from an international expert panel. ☐ Diagnosis and management of mastocytosis: an emerging challenge in applied hematology ☐ Diagnosis and treatment of primary myelodysplastic syndromes in adults: recommendations from the European LeukemiaNet ☐ ECIL guidelines for preventing Pneumocystis jirovecii pneumonia in patients with haematological malignancies and stem cell transplant recipients. ☐ ECIL guidelines for the diagnosis of Pneumocystis jirovecii pneumonia in patients with haematological malignancies and stem cell transplant recipients ☐ ECIL guidelines for the prevention, diagnosis and treatment of BK polyomavirus-associated haemorrhagic cystitis in haematopoietic stem cell transplant recipients ☐ ECIL guidelines for treatment of Pneumocystis jirovecii pneumonia in non-HIV-infected haematology patients ☐ ECIL-6 guidelines for the treatment of invasive candidiasis, aspergillosis and mucormycosis in leukemia and hematopoietic stem cell transplant patients ☐ European LeukemiaNet recommendations for the management and avoidance of adverse events of treatment in chronic myeloid leukaemia ☐ European LeukemiaNet recommendations for the management of chronic myeloid leukemia: 2013. ☐ Fluoroquinolone prophylaxis in haematological cancer patients with neutropenia: ECIL critical appraisal of previous guidelines ☐ Harmonemia: a universal strategy for flow cytometry immunophenotyping-A European LeukemiaNe WP10 study ☐ Management of Epstein-Barr Virus infections and post-transplant lymphoproliferative disorders in patients after allogeneic hematopoietic stem cell transplantation: Sixth European Conference on Infections in Leukemia (ECIL-6) guidelines. ☐ Management of acute promyelocytic leukemia: recommendations from an expert panel on behalf of the European LeukemiaNet ☐ Management of viral hepatitis in patients with haematological malignancy and in patients undergoing haemopoietic stem cell transplantation: recommendations of the 5th European Conference on Infections in Leukaemia (ECIL-5) ☐ Minimal/measurable residual disease in AML: a consensus document from the European LeukemiaNet MRD Working Party. ☐ NCCN Guidelines Insights: Myeloproliferative Neoplasms, Version 2.2018. ☐ Philadelphia-negative classical myeloproliferative neoplasms: critical concepts and management recommendations from European LeukemiaNet. ☐ Pneumocystis jirovecii pneumonia: still a concern in patients with haematological malignancies and stem cell transplant recipients ☐ Proposals for revised IWG 2018 hematological

response criteria in patients with MDS included in clinical trials.
- ☐ Revised response criteria for myelofibrosis: International Working Group-Myeloproliferative Neoplasms Research and Treatment (IWG-MRT) and European LeukemiaNet (ELN) consensus report.
- ☐ Revised response criteria for polycythemia vera and essential thrombocythemia: an ELN and IWG-MRT consensus project.
- ☐ The EBMT-ELN working group recommendations on the prophylaxis and treatment of GvHD: a change-control analysis.
- ☐ Which patients with myelofibrosis should receive ruxolitinib therapy? ELN-SIE evidence-based recommendations
- ☐ No CPGs-CDMTs adopted for this Subnetwork

Additional CPG/CDMTs adopted

- ◯ Yes
- ◯ No

Please enter the CPGs - CDMTs activity number: [current-instance]

Name additional CPG/CDMTs adopted

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Calculation name additional CPG/CDMTs adopted

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Link additional CPG/CDMTs adopted

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Count activity

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If you have to enter an additional CPGs-CDMTs click the 'Add additional CPGs-CDMTs adopted' button below.

If all additional CPGs-CDMTs adopted have been entered, click the 'Submit' button to finalize the entry process for CPGs-CDMTs.

If you want to remove the information provided in this form, select "No" in the first question "Additional CPG/CDMTs adopted"

Survey Completion Confirmation

Please check the _____ surveys list to make sure you haven't left any unverified item and are ready to submit the survey.

224) Finish the submission?

◯ Yes
◯ No