ERN | EuroBloodNet

ERN-EuroBloodNet

Continuous Monitoring Survey

User Handbook – 2024/2025 Campaign

European Reference Network | Hematological Diseases (ERN EuroBloodNet)

Co-funded by the European Union

Content

List of Acronyms

APs - Affiliated Partners

DGs – Disease Groups

ERNs – European Reference Networks

HCP – Healthcare provider

RHDs – Rare Hematological diseases

RHD-DG – Rare Hematological Diseases-Disease Groups

1. ERN-EuroBloodNet Continuous Monitoring Survey

Introduction and Context

At the outset of the ERN initiative, the Board of Member States approved seven areas of intervention for ERNs. For each area, an objective and indicators were defined and agreed by all ERNs, becoming the core set of ERN indicators. This set was used from 2017 to 2023, with minor changes and clarifications to the definitions over time.

The continuous monitoring of ERNs is based on a single data collection per year covering the period from January to December of the previous year.

To simplify data collection and reporting, DG Sante has implemented a data collection platform for ERNs Members and Affiliated Partners which is used to gather the number of new patients referred to the Healthcare Provider (HCP) and the use of Orphacodes.

Concerning the rest of the indicators, ERN-EuroBloodNet has implemented the "**Continuous Monitoring Survey**" to collect standardized information through a secured REDCap system.

Who can contribute?

The Continuous Monitoring Survey is currently exclusively opened to HCPs Members and Affiliated partners within the ERN-EuroBloodNet; 90 and 7 HCPs respectively.

Invitations to participate will be received by the HCP Representative, Substitute and Data Reporter.

The link is customized for each HCP, but it can be shared within your HCP to facilitate the completion of the survey.

How does the Continuous Monitoring Survey work?

The Continuous Monitoring Survey has been implemented using REDCap system, a secure web platform for managing online databases. This system handles data collection for HCPs and ensures the data can be effectively analysed and extracted after collection.

The Continuous Monitoring Survey is composed by different sections according to the specific objectives set out by DG Sante:

1. Education and Training
2. Clinical Trials
3. Observational Studies
4. Publications
5. Communication and Dissemination
6. Clinical Practice Guidelines and Clinical Decision-Making Tools

Mandatory & Optional information

Each HCP is **required to respond the surveys of the subnetworks where the institution is nationally recognized** as Member or Affiliated Partner. However, the opportunity to contribute is also extended to other subnetworks.

- **Reported actions linked to:**
  - **HCP's subnetworks of expertise and**
  - **Complying with the Eligibility criteria for the Continuous Monitoring**

  will be counted for the Continuous Monitoring of the HCP

- **Reported actions linked to:**
  - **Other subnetworks and/or**
  - **Not complying with the Eligibility criteria for the Continuous Monitoring**

  will be collected for the next 5 years Evaluation as evidence for your activity

You will find at the beginning of the Survey the subnetworks of expertise for your HCP.

Below and in each Section of the Survey is a summary of the required information and Eligibility criteria for the Continuous Monitoring.

In addition, you can find information on the parameters' definitions and the items listed in the Dropdown lists in the "Continuous Monitoring - Annex".

Deadlines

The 2025 campaign will **collect the data from 1st January to 31st December 2024.**

Invited experts to participate will have access to the Continuous Monitoring Survey:

- Survey's opening date: **3rd February 2025**
- Survey's closing date: **28th February 2025 (23:59 CET)**

Helpdesk

The person on the ERN-EuroBloodNet team responsible of this action is Giulio Sannasardo (giulio.sannasardo@aphp.fr). Do not hesitate to contact him for any doubt or request of assistance.

2. Data Entry on the Continuous Monitoring Survey

Accessing the Survey

Each HCP Representative will receive an automatic e-mail from the platform including access link (red square in Figure 1).

Dear Carles Garcia,

We are contacting you for the **Continuous Monitoring Exercise - Reporting period 1st January 2024 - 31st December 2024.**

As anticipated, we are launching the new "ERN-EuroBloodNet Continuous Monitoring Survey", a REDCap system to facilitate annual data collection avoiding tedious Excels templates as previous years.

- **Access the survey here: ERN-EuroBloodNet Continuous Monitoring Survey 2025**
  - ~~HCP Representatives, Substitutes, and Data Reporters will receive the access link.~~
  - Link is customized for each HCP, but it can be shared within your HCP to facilitate the completion of the survey by different persons if needed.
- **"Save & Return Later"** button gives the possibility to save the data without submitting.
- **"Handbook for Continuous Monitoring Survey 2025"** includes data parameters that are requested and eligibility criteria for the Continuous Monitoring.

Deadline: 28th February 2025 (23:59 CET).

Thank you for your cooperation.

Best,
ERN-EuroBloodNet Coordination Team

European Reference Network
for rare or low prevalence complex diseases

FIGURE 1. Invitation Email

We will also share the link to Substitutes and Data Reporters (for those HCPs that have indicated one last year).

By accessing the link, you will enter the "Survey queue" section, where you can find general information about the survey, and the different sections to complete.

Survey queue section

Reported actions need to be linked to predefined Rare Hematological Disease Groups (RHD-DGs). RHDs are distributed into 6 subnetworks, 2 oncological and 4 non-oncological, and grouped in 72 RHD-DGs.

Each HCP is required to respond the surveys of the subnetworks where the institution is nationally recognized as Member or Affiliated Partner. However, the opportunity to contribute is also extended to other subnetworks as explained in the "Survey queue" section (red square in Figure 2).

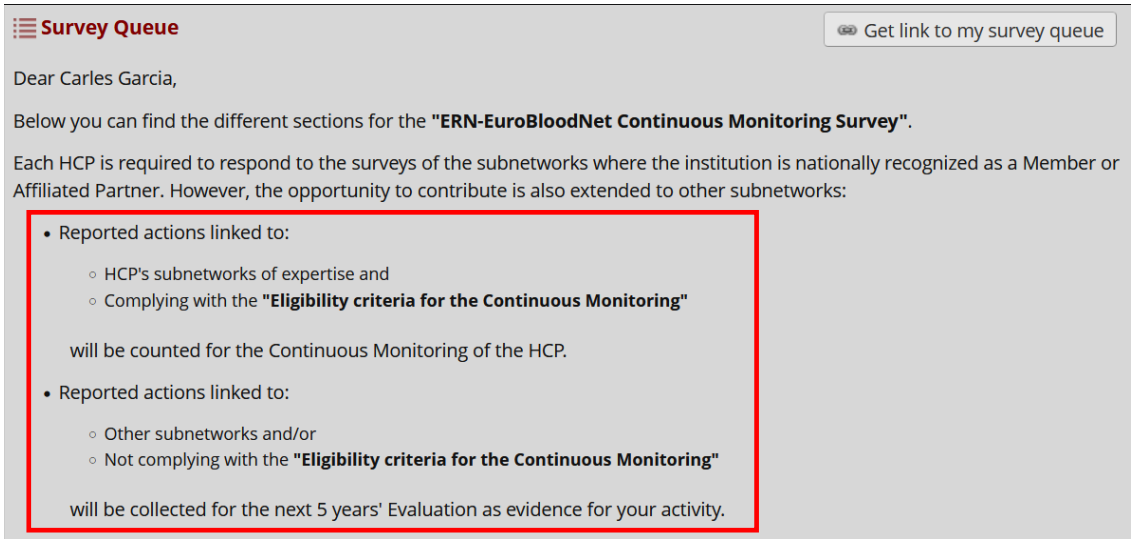

FIGURE 2. Survey queue section explaining how contributions are counted

In the same page you will find the subnetworks of expertise for your HCP (red square in Figure 3).

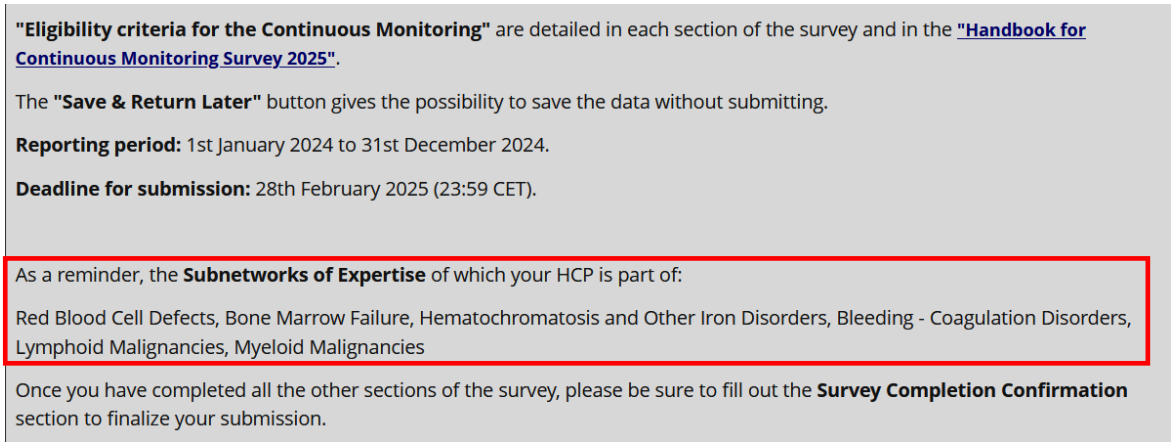

FIGURE 3. Survey queue section showing the HCP's Subnetworks of expertise

Below, you can access the different forms to provide information on each section by using the "Begin section" button (Figure 4).

FIGURE 4. Sections to complete the Continuous Monitoring Survey

Steps for data entry

In each section you will find the "Instructions" and "Eligibility criteria" for the current section, and a button to return to the "Survey queue".

These are the steps to introduce data in the Education and Training activities as shown in Figure 5, applicable to all the sections:

- To begin introducing data select "Yes" to the question "Do you have any Education/Training activities to report", which will expand the questionnaire to be completed. If you don't have any activity for this section select "No" and submit.
- Once completed, to add a new activity for this section use the button "Add another Training and Education activity".
- Once all activities for this section are completed, you can use the "Submit" button to finalize this section, and access the "Survey queue" again.
- Use the "Save & Return Later" button to save the data without submitting that specific form.

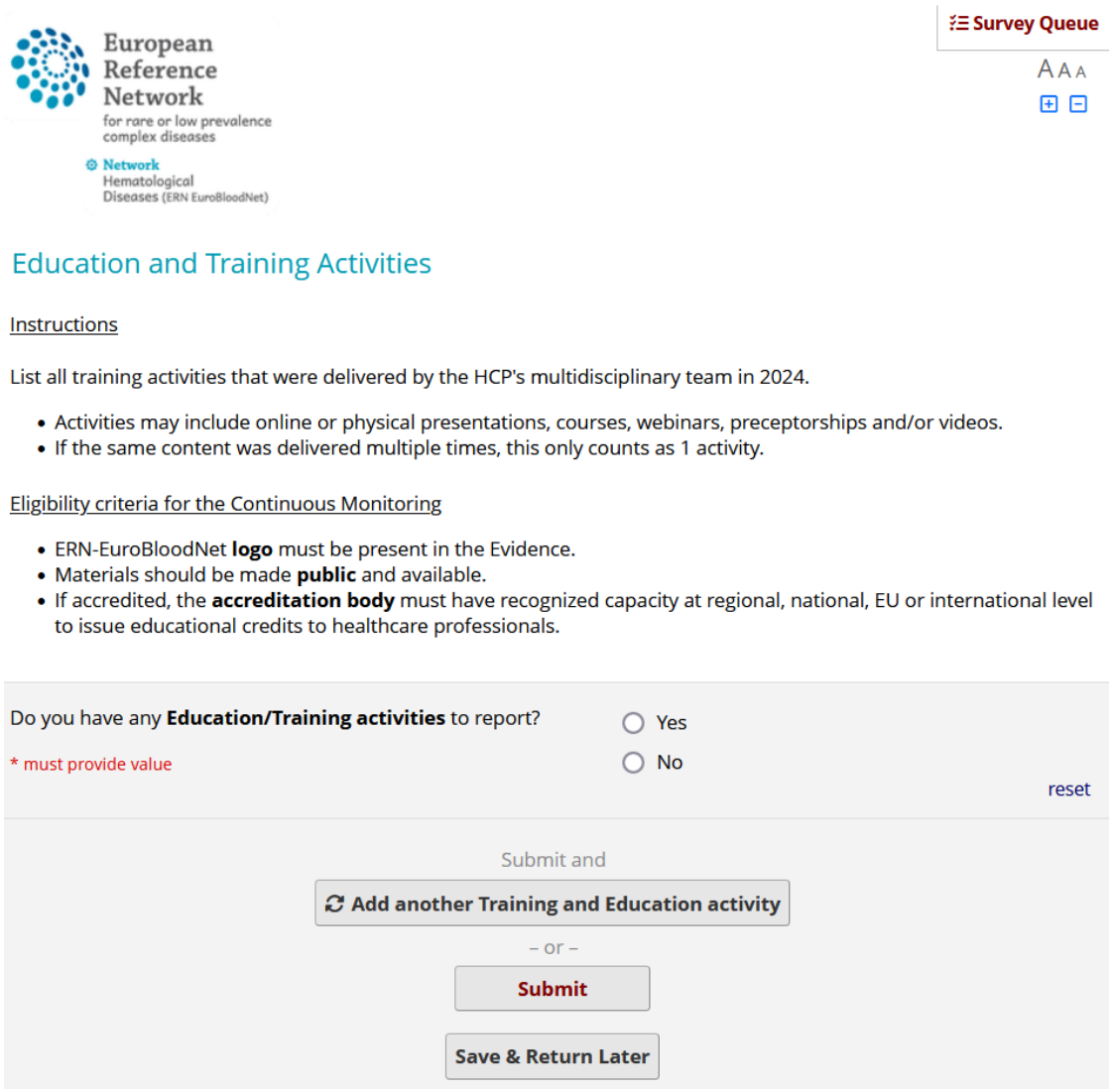

FIGURE 5. Education and Training Activities section

Steps for data entry (CPGs-CDMTs section)

In the Clinical Practice Guidelines (CPGs) and Clinical Decision-Making Tools (CDMTs) section, you will be able to directly select all the CPGs-CDMTs from the Subnetworks from which your HCP is an expert (Figure 6).

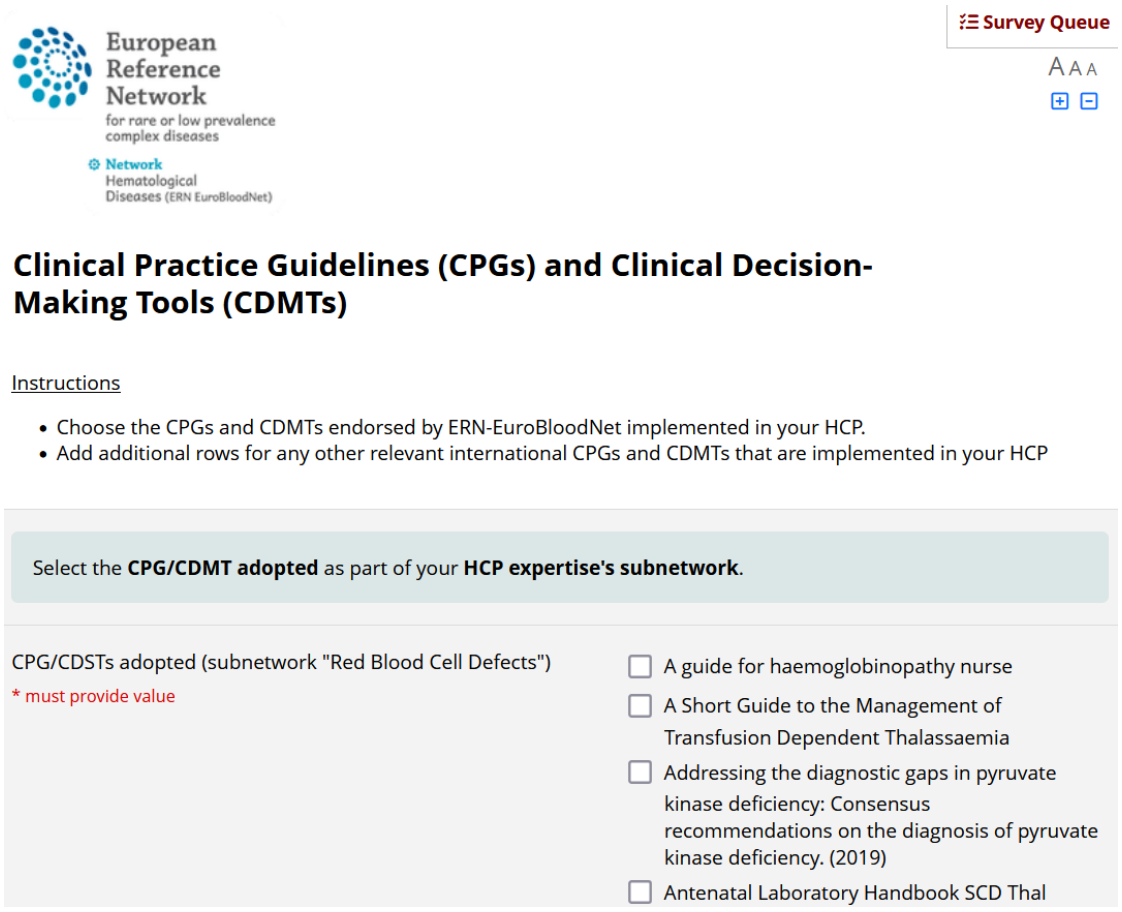

FIGURE 6. Example of the CPGs-CDMTs section for an expert from the Subnetwork "Red Blood Cell Defects"

At the bottom of the same form you will be able to add additional CPGs-CDMTs used by your HCP not linked to your HCP's expertise (Figure 7).

FIGURE 7. Section to add additional CPGs-CDMTs

3. Save and Submit the data from the Continuous Monitoring Survey

Saving and modifying data

Once you begin to submit forms, these will appear in the "Survey queue" section. Figure 8 shows an example of a survey with 2 Education and Training activities and 3 Clinical Trials submitted. Here you can:

- Edit each individual form using the "Edit response" button.
- Add a new activity using e.g. "Add another Clinical Trial".
- Begin adding data to new sections.

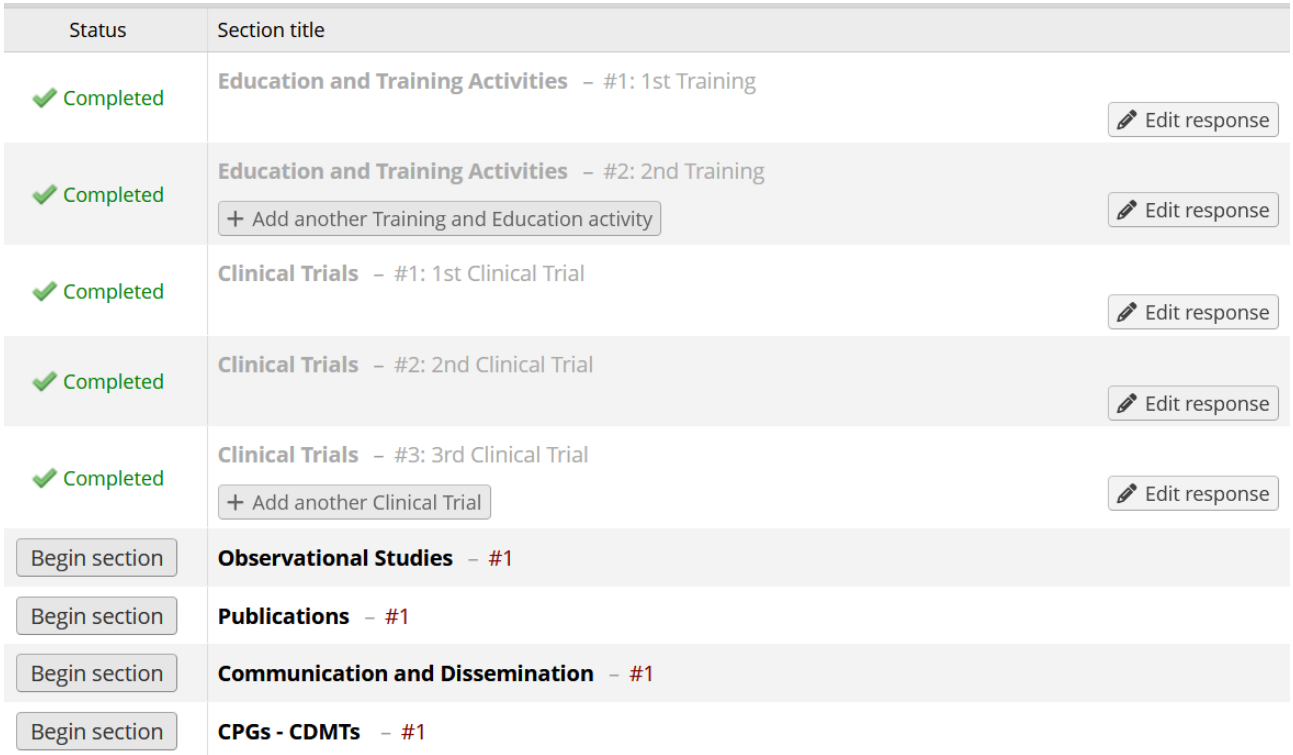

FIGURE 8. Survey queue for the Continuous Monitoring

Be aware that, as you enter data, not all rows will be visible to keep the view uncluttered. You can click 'View all' to expand and display all hidden rows if needed ("View all" button as shown in Figure 9).

Survey Completion Confirmation

Once you have completed all the forms, a new "Survey Completion Confirmation" section will appear as shown in Figure 9.

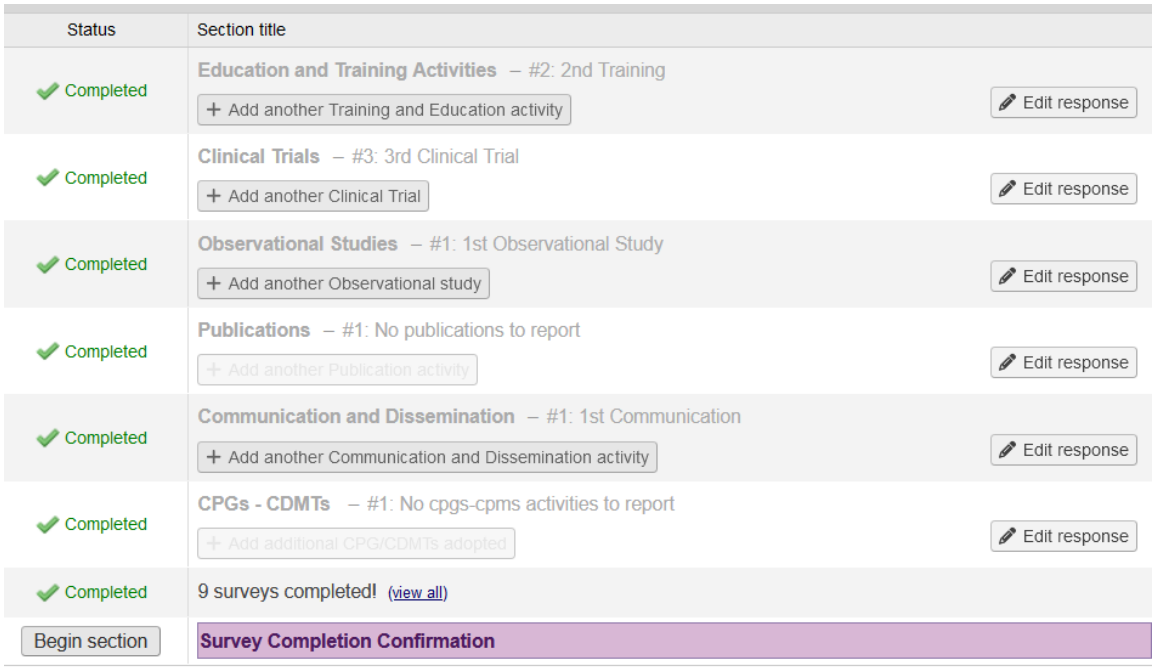

FIGURE 9. Survey queue showing the "Survey Completion Confirmation" section after all the survey has been completed

Once all the information for the different sections has been completed, you can enter it (Figure 10) and select "Yes" and "Submit", which will confirm the Continuous Monitoring for your HCP has been completed.

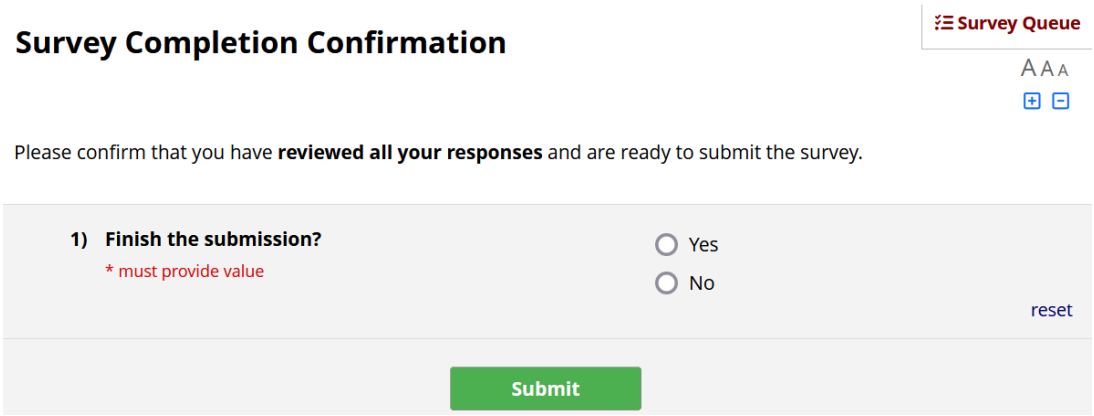

FIGURE 10. Last step to confirm the completion of the Continuous Monitoring Survey

4. Required information for each section of the Continuous Monitoring Survey

Here you have a summary of the required information and Eligibility criteria for the Continuous Monitoring. In addition, you can find information on the parameters' definitions and the items listed in the "Continuous Monitoring - Annex".

Education and Training

Instructions

List all training activities that were delivered by the HCP's multidisciplinary team in 2024.

- 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

Information requested

Diseases covered	Experts	Role	Patients' association	Type of educational resource	Title	Start date	End date	Evidence (Link)	Logo	Target	Accreditation	Number of credits	Type of credits	Number of participants	Number of countries of participants
DL 1, 2, 3, 4, 5, 6, 7	DL8	DL 9	Yes/No (if "Yes" add name)	DL 14	Free text	Date	Date	Free text	Yes/No	DL15	Yes/No (if "Yes" add name)	Number	DL 16	Number	Number

DL: Dropdown list (lists available in Continuous Monitoring Survey- Annex)

Clinical Trials

Instructions

List all Clinical Trials that were active in 2024.

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)

Information requested

Diseases covered	Experts	Role	Patients' association	Title	Start date	End date	At least 2 ERN-EuroBloodNet Members/APs from 2 Member States	Members/APs	Public repository	ID
DL 1, 2, 3, 4, 5, 6, 7	DL8	DL 10	Yes/No (if "Yes" add name)	Free text	Date	Date	Yes/No	DL 17	DL 18	Free text

DL: Dropdown list (lists available in Continuous Monitoring Survey- Annex)

Observational studies

Instructions

List all observational studies that were active in 2024. 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**

Information requested

Diseases covered	Experts	Role	Patients' association	Title	Start date	End date	At least 2 ERN-EuroBloodNet Members/APs from 2 Member States	Members/Aps	Public repository	ID	Acknowledgement
DL 1, 2, 3, 4, 5, 6, 7	DL8	DL 11	Yes/No (if "Yes" add name)	Free text	Date	Date	Yes/No	DL 17	DL 18	Free text	Yes/No

DL: Dropdown list (lists available in Continuous Monitoring Survey- Annex)

Publications

Instructions

Accepted peer-reviewed publications in scientific journals in 2024.

Eligibility criteria for the Continuous Monitoring

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

Information requested

Diseases covered	Experts	Role	Patients' association	Title	Publication date	At least 2 ERN-EuroBloodNet Members/APs from 2 Member States	Members/APs	Pubmed DOI Code	Acknowledgement
DL 1, 2, 3, 4, 5, 6, 7	DL8	DL 12	Yes/No (if "Yes" add name)	Free text	Date	Yes/No	DL 17	Free text	Yes/No

DL: Dropdown list (lists available in Continuous Monitoring Survey- Annex)

Communication and dissemination

Instructions

List all Congresses/Conferences/Meetings at which the ERN-EuroBloodNet activities and results were presented in 2024.

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

Information requested

Diseases covered	Experts	Role	Patients' association	Title of the Event (Congress...)	Start date	End date	Title of the Presentation	Evidence (Link)	Logo	Target
DL 1, 2, 3, 4, 5, 6, 7	DL8	DL 13	Yes/No (if "Yes" add name)	Free text	Date	Date	Free text	Free text	Yes/No	DL15

DL: Dropdown list (lists available in Continuous Monitoring Survey- Annex)

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.

Information requested

CPG/CDMT adopted as part of the HCP expertise's subnetwork	Additional CPG/CDMTs adopted	Name additional CPG/CDMTs adopted	Link additional CPG/CDMTs adopted
Yes/No (if "Yes" DL 19, 20, 21, 22, 23, 24)	Yes/No	Free text	Free text

DL: Dropdown list (lists available in Continuous Monitoring Survey- Annex)

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CONTINUOUS MONITORING SURVEY

ANNEX

Glossary and Dropdown Lists

Glossary of information requested

Disease Group	Indicate into which Disease Group does the activity fall into. You'll be able to choose from dropdown lists for each subnetwork (DL 1, 2, 3, 4, 5, 6, 7)
Experts	Refers to the Expert that led/participated in the activity. You will be able to choose from a dropdown list (DL 8, not shown in annex) of Experts linked to your HCP. You can select "Other" and type the name if the expert is not present in the list.
Role	Refers to the Role of the Expert in the activity (DL 9, 10, 11, 12, 13 specific for each section)
Patients' association	Patients associations actively involved in the coordination of the action
Type of educational resource	Type of the activity (DL 14)
Title	Indicate the title of the activity
Start Date	The date the activity started
End Date	The date the activity ended (if applicable)
Evidence (Link)	Evidence of the activity reported. This evidence can be a link to the website/page/agenda of the activity
Logo	Presence of the ERN-EuroBloodNet logo in the activity
Target	Target of the activity (DL 15)
Accreditation	In case the activity was accredited. If you select it, you will need to provide the "Accreditation body", "Nº of credits" and "Type of credits (DL 16)"
Number of Participants	Number of participants in the activity
Number of Countries of Participants	Number of countries of the participants in the activity
At least 2 ERN-EuroBloodNet Members/APs from 2 Member States	In case there are at least 2 ERN-EuroBloodNet Members or Afiiliated Partners from 2 different EU Member States participating in the activity.
Members/Aps	List of Members / Associated partners to be selected (DL 17)
Public repository	In case the activity is registered in a Public repository (DL 18)
ID	ID code of the activity
Acknowledgement	If the activity has obtained an official acknowledgement
Publication date	Day in which publication was published
Pubmed DOI Code	DOI code of publication
Title of the Event (Congress...)	Title of the event
Title of the Presentation	Title of the presentation
CPG/CDMT adopted as part of the HCP expertise's subnetwork	Clinical Practice Guidelines and Clinical Decision-Making Tools endorsed by ERN-EuroBloodNet implemented by your centre for your subnetworks of expertise. You will be able to choose from dropdown lists for each subnetwork (DL 19, 20, 21, 22, 23, 24)
Additional CPG/CDMTs adopted	Other Clinical Practice Guidelines and Clinical Decision-Making Tools adopted by your centre

Dropdown lists

Dropdown list 01: Diseases covered
All RHDs
Red Blood Cell Defects subnetwork
Bone Marrow Failure subnetwork
Hematochromatosis and Other Iron Disorders subnetwork
Bleeding - Coagulation Disorders subnetwork
Lymphoid Malignancies subnetwork
Myeloid Malignancies subnetwork

Dropdown list 02: 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

Dropdown list 03: 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

Dropdown list 04: 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

Dropdown list 05: 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

Dropdown list 06: 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

Dropdown list 07: 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

Dropdown list 08: Experts
List only available in survey's dropdown

Dropdown list 09: Role education and training
Coordinator Webinar program
Speaker Webinar
Coordinator of online/onsite training courses
Coordinator Preceptorship
Host Preceptorship

Dropdown list 10: Role clinical trials
Coordinator clinical trial
Participant clinical trial

Dropdown list 11: Role observational studies
Coordinator observational study
Participant observational study

Dropdown list 12: Role publications
1st author Publication
Co-author Publication

Dropdown list 13: Role dissemination
Presenter
Other

Dropdown list 14: Type of educational resource
Onsite/Online training courses
Webinars
Precertorships
Videos
Other

Dropdown list 15: Target
Healthcare professionals (physicians, nurses, etc)
Patients (patients community, patients advocates, patients organizations)
Public at large
Other

Dropdown list 16: Type of credits
Continuing Medical Education (CME)
European Credit Transfer System (ECTS)
Other

Dropdown list 17: Members / Affiliated Partners
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

Dropdown list 18: Public repository
Clinicaltrial.gov
Other

Dropdown list 19: CPG/CDMTs adopted (subnetwork "Red Blood Cell Defects")
Guidelines for the diagnosis and management of hereditary spherocytosis – 2011 update
ICSH guidelines for the laboratory diagnosis of nonimmune hereditary red cell membrane disorders
Standards for the clinical care of children and adults with thalassaemia in the UK
Recommendations regarding splenectomy in hereditary hemolytic anemias.
Management of Non-Transfusion-Dependent Thalassemia: A Practical Guide
EMQN Best Practice Guidelines for molecular and haematology methods for carrier identification and prenatal diagnosis of the haemoglobinopathies
Significant haemoglobinopathies: guidelines for screening and diagnosis
NHS SCT Handbook for Newborn Laboratories
Antenatal Laboratory Handbook SCD Thal
Evidence-Based Management of Sickle Cell Disease: Expert Panel Report, 2014
ENERCA clinical recommendations for disease management and prevention of complications of sickle cell disease in children
Recommended methods for the characterization of red cell pyruvate kinase variants
Clinical Pharmacogenetics Implementation Consortium (CPIC) guidelines for rasburicase therapy in the context of G6PD deficiency genotype.
Preterm Neonates: Beyond the Guidelines for Neonatal Hyperbilirubinemia
Guidelines for the diagnosis, investigation and management of polycythaemia/erythrocytosis
Prevention and Diagnosis of Haemoglobinopathies: A Short Guide for Health Professionals and Laboratory Scientists (2016)
Guidelines for the management of non transfusion dependent thalassaemia (NTDT) 2ND edition
A guide for haemoglobinopathy nurse
Prevention of Thalassaemias and other Haemoglobin Disorders, Vol 1, 2nd Edition (2013)
A Short Guide to the Management of Transfusion Dependent Thalassaemia
Emergency Management of Thalassaemia (2012)
Guidelines for the Management of Transfusion Dependent Thalassaemia, 3rd Edition (2014)
Prevention of Thalassaemias and Other Haemoglobin Disorders, Vol. 2: Laboratory Protocols (2012)
Addressing the diagnostic gaps in pyruvate kinase deficiency: Consensus recommendations on the diagnosis of pyruvate kinase deficiency. (2019)
Newborn screening for sickle cell disease in Europe: recommendations from a Pan-European Consensus Conference
Recommendations for diagnosis and treatment of methemoglobinemia
Guidelines for the Management of Transfusion-Dependent Thalassaemia (4th Edition - 2021)
International Guidelines for the Diagnosis and Management of Pyruvate Kinase Deficiency

Dropdown list 20: CPG/CDMTs adopted (subnetwork "Bone Marrow Failure")
Diagnosis and management of congenital dyserythropoietic anemias
Diagnosing and treating Diamond Blackfan anaemia: results of an international clinical consensus conference
How I treat Diamond-Blackfan anemia
Guidelines for the diagnosis and management of adult aplastic anaemia
How I manage patients with Fanconi anaemia
How I treat MDS and AML in Fanconi anemia
Paroxysmal nocturnal hemoglobinuria
Paroxysmal Nocturnal Hemoglobinuria
Haematopoietic and immune defects associated with GATA2 mutation
GATA2 deficiency and related myeloid neoplasms
Transplantation for bone marrow failure: current issues
Recommendations on hematopoietic stem cell transplantation for inherited bone marrow failure syndromes
Recommendations regarding splenectomy in hereditary hemolytic anemias

Dropdown list 21: CPG/CDMTs adopted (subnetwork "Hematochromatosis and Other Iron Disorders")
The quality of hereditary haemochromatosis guidelines: a comparative analysis
European Association For The Study Of The Liver. EASL clinical practice guidelines for HFE hemochromatosis
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)
Reassessing the Safety Concerns of Utilizing Blood Donations from Patients with Hemochromatosis. Hepatology
Molecular diagnosis of hemochromatosis
Practice guidelines for the diagnosis and management of microcytic anemias due to genetic disorders of iron metabolism or heme synthesis
Therapeutic recommendations in HFE hemochromatosis for p.Cys282Tyr (C282Y/C282Y) homozygous genotype
Key-interventions derived from three evidence based guidelines for management and follow-up of patients with HFE haemochromatosis

Dropdown list 22: CPG/CDMTs adopted (subnetwork "Bleeding - Coagulation Disorders")
WFH Guidelines: Guidelines for the management of haemophilia
Guideline on the management of haemophilia in the fetus and neonate
Practice Guidelines for the Molecular Diagnosis of Haemophilia A
Practice Guidelines for the Molecular Diagnosis of Haemophilia B

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
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
A review of inherited platelet disorders with guidelines for their management on behalf of the UKHCDO
The molecular analysis of von Willebrand disease: a guideline from the UK Haemophilia Centre Doctors' Organisation Haemophilia Genetics Laboratory Network
Management of von Willebrand's disease: a guideline from the UK Haemophilia Centre Doctors' Organisation
The diagnosis of von Willebrand's disease: a guideline from the UK Haemophilia Centre Doctors' Organisation
Emergency and out of hours care for patients with bleeding disorders – Standards of care for assessment and treatment
A framework for genetic service provision for haemophilia and other inherited bleeding disorders
UKHCDO guidelines on the management of HCV in patients with hereditary bleeding disorders 2011.
Guideline on the diagnosis and management of chronic liver disease in haemophilia
The diagnosis and management of factor VIII and IX inhibitors: a guideline from the United Kingdom Haemophilia Centre Doctors Organisation
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
Guidelines for the management of acute joint bleeds and chronic synovitis in haemophilia: A United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO) guideline.
Primary prophylaxis in haemophilia care: Guideline update 2016
European principles of inhibitor management in patients with haemophilia.
Guidelines on the diagnosis and management of thrombotic thrombocytopenic purpura and other thrombotic microangiopathies.
Diagnostic and treatment guidelines for thrombotic thrombocytopenic purpura (TTP) 2017 in Japan

Dropdown list 23: CPG/CDMTs adopted (subnetwork "Lymphoid Malignancies")
ESMO Guidelines consensus conference on malignant lymphoma 2011 part 1: diffuse large B-cell lymphoma (DLBCL), follicular lymphoma (FL) and chronic lymphocytic leukemia (CLL)
ESMO Consensus conferences: guidelines on malignant lymphoma. part 2: marginal zone lymphoma, mantle cell lymphoma, peripheral T-cell lymphoma
Hairy cell leukaemia: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up
AL amyloidosis: from molecular mechanisms to targeted therapies
Update on nodal and splenic marginal zone lymphoma
Acute lymphoblastic leukemia in adult patients: ESMO clinical practice guidelines for diagnosis, treatment and follow-up

Acute lymphoblastic leukemia: Version 2.2015
Gastric marginal zone lymphoam of MALT type: ESMO clinical practice guidelines for diagnosis, treatment and follow-up
Guidelines on the management of AL amyloidosis
Hodgkin´s lymphoma: ESMO clinical practice guidelines on diagnosis, treatment and follow up
Hodgkin lymphoma, Version 1.2017
Hodgkin´s lymphoma in adults: diagnosis, treatment and follow-up
Guideline for the diagnosis, treatment and response criteria for Bing-Neel syndrome
Response assessment in Waldenström macroglobulinaemia: update from the VIth International Workshop
Guidelines for Diagnosis, Indications for Treatment, Response Assessment and Supportive Management of Chronic Lymphocytic Leukemia
Investigation and management of IgM and Waldenström-associated peripheral neuropathies: recommendations from the IWWM-8 consensus panel
Treatment recommendations from the Eighth International Workshop on Waldenström's Macroglobulinemia
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.
Immunoglobulin gene sequence analysis in chronic lymphocytic leukemia: updated ERIC recommendations.
High-risk chronic lymphocytic leukemia in the era of pathway inhibitors: integrating molecular and cellular therapies.
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
ERIC recommendations for TP53 mutation analysis in chronic lymphocytic leukemia-update on methodological approaches and results interpretation.

Dropdown list 24: CPG/CDMTs adopted (subnetwork "Myeloid Malignancies")
Diagnosis and treatment of primary myelodysplastic syndromes in adults: recommendations from the European LeukemiaNet
Diagnosis and management of AML in adults: 2017 ELN recommendations from an international expert panel.
NCCN Guidelines Insights: Myeloproliferative Neoplasms, Version 2.2018.
Management of acute promyelocytic leukemia: recommendations from an expert panel on behalf of the European LeukemiaNet
Diagnosis and management of mastocytosis: an emerging challenge in applied hematology
Allogeneic hematopoietic stem cell transplantation for MDS and CMML: recommendations from an international expert panel.
Minimal/measurable residual disease in AML: a consensus document from the European LeukemiaNet MRD Working Party.
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.
Philadelphia-negative classical myeloproliferative neoplasms: critical concepts and management recommendations from European LeukemiaNet.
An international consortium proposal of uniform response criteria for myelodysplastic/myeloproliferative neoplasms (MDS/MPN) in adults.
European LeukemiaNet recommendations for the management of chronic myeloid leukemia: 2013.
European LeukemiaNet recommendations for the management and avoidance of adverse events of treatment in chronic myeloid leukaemia
Which patients with myelofibrosis should receive ruxolitinib therapy? ELN-SIE evidence-based recommendations
Harmonemia: a universal strategy for flow cytometry immunophenotyping-A European LeukemiaNet WP10 study
The EBMT-ELN working group recommendations on the prophylaxis and treatment of GvHD: a change-control analysis.
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)
ECIL guidelines for treatment of Pneumocystis jirovecii pneumonia in non-HIV-infected haematology patients
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
Pneumocystis jirovecii pneumonia: still a concern in patients with haematological malignancies and stem cell transplant recipients
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.
ECIL guidelines for the prevention, diagnosis and treatment of BK polyomavirus-associated haemorrhagic cystitis in haematopoietic stem cell transplant recipients
Fluoroquinolone prophylaxis in haematological cancer patients with neutropenia: ECIL critical appraisal of previous guidelines
ECIL-6 guidelines for the treatment of invasive candidiasis, aspergillosis and mucormycosis in leukemia and hematopoietic stem cell transplant patients
Proposals for revised IWG 2018 hematological response criteria in patients with MDS included in clinical trials.