



European Rare Blood
Disorders Platform

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

User Manual – 2025



European
Reference
Network

Hematological
Diseases (ERN EuroBloodNet)



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List of Acronyms

DGs – Disease Groups

HCP – Healthcare provider

RHDs – Rare Hematological diseases

RHD-DG – Rare Hematological Diseases-Disease Groups

1. ENROL EpiBlood

1.1. What is ENROL EpiBlood?

EpiBlood, the ENROL registry module, collects annually the total number of patients and new patients affected by Rare Hematological Diseases (RHDs), contributing to the establishment of the disease population baseline (real number of patients). [This baseline is required according to EMA quality criteria to understand the ENROL registry population coverage \(patients included in the registry\) and possible sources of bias.](#)

ENROL EpiBlood has been implemented using REDCap, a secure web platform for managing online databases and surveys. The module consists of six surveys, structured according to ENROL RHDs coverage into the following subnetworks:

1. Myeloid malignancies.
2. Lymphoid malignancies.
3. Red blood cell defects.
4. Bleeding-Coagulation disorders.
5. Bone marrow failure and hematopoietic disorders.
6. Hemochromatosis and other iron related disorders.

1.2. Who can contribute?

ENROL EpiBlood is currently exclusively opened to Members and Affiliated partners within the ERN-EuroBloodNet; 89 and 7 Healthcare providers (HCP) respectively. Invitations to participate will be exclusively received by the data entry appointed by each HCP.

[The module is expected to be opened soon to other EU healthcare providers out of the scope of the ERN to increase the completeness of data coverage.](#)

1.3. Mandatory & Optional Surveys

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

1.4. Data to be reported

ENROL EpiBlood 2025 will collect the annual count of RHDs patients of year 2025.

RHDs are distributed into 6 subnetworks, 2 oncological and 4 non-oncological, and grouped in 72 Rare Hematological Diseases-Disease Groups (RHD-DG).

Data collection is performed at RHD-DG level.

Different variables according to the type of subnetwork are requested. The annex 1 of this document includes the surveys templates aiming to help the participant to be prepared before the opening of the surveys.

Data to be collected for onco-surveys*:

- Number of **new** adult patients (≥ 18 years) referred to the Health Care Providers participating in the ERN diagnosed with this disease group
 - o **Number of new female adult patients (≥ 18 years)**
 - o **Number of new male adult patients (≥ 18 years)**

Data to be collected for non-onco-surveys*:

- Number of **total** patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group
 - o **Number of total pediatric patients (<18 years)**
 - o **Number of total adult patients (≥ 18 years)**
 - o **Number of total female patients**
 - o **Number of total male patients**
- Number of **new** patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group
 - o **Number of new pediatric patients (<18 years)**
 - o **Number of new adult patients (≥ 18 years)**
 - o **Number of new female patients**
 - o **Number of new male patients**

****Please, see the survey template available in the ERN-EuroBloodNet webpage for further details. Read carefully the definitions of each variable.***

1.5. Deadlines

The survey will remain opened during two months.

Accordingly, access will be granted during the data collection period:

- Survey opening: **2nd March 2026.**
- Survey closing: **28th April 2026.**

1.6. Helpdesk

The person on the ENROL team responsible of this action is Maximo Tartaglia (maximo.tartaglia@vhir.org). Do not hesitate to contact him for any doubt or request of assistance.

2. Steps for data entry in REDCap

2.1. Access the survey and include data

After survey opening on the **2nd of March 2026**, each HCP designated data entry will receive an e-mail from the platform including a unique access link.

Dear Maximo Tartagli,

Welcome to ENROL EpiBlood 2025, the Registry Module for the Collection of annual counts of patients with RHDs from **2025**.

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

You are receiving this e-mail because you are a reference person for your center to contribute to this action.

The ENROL EpiBlood module has been developed to systematically collect standardized information on the annual counts of patients with RHDs through a secured [REDCap system](#).

To open the module click here: [ENROL EpiBlood](#)

If it does not work, copy the link below into your web browser:
<https://redcap.vhirl.org/redcap/surveys/?s=uAVd8IMJkMawJdp>

The submission and edition of data is available until the 28th of April 2026 (23:59 CEST).

For further information you can visit [ENROL EpiBlood Documents](#)

Do not hesitate to contact maximo.tartaglia@vhirl.org for any request.

Thank you so much for your collaboration,


ENROL coordination team



FIGURE 1. INVITATION E-MAIL

Once the survey is accessed through the link, two different buttons are available in the welcoming section:



- A. **START THE SURVEY:** To begin the survey by having access to the questions of the first subnetwork, in the order listed in section 1.1.
- B. **SURVEY QUEUE:** To have access to the list of all subnetwork's surveys. You will be able to specifically select and open the surveys one by one.



European Rare Blood Disorders Platform

Survey Queue

AAA



Dear Maximo Tartagli,

Welcome to ENROL EpiBlood 2025, the Registry Module for the Collection of annual counts of patients with RHDs from **2025**.

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


Your center contribution is **mandatory** for subnetworks **Lymphoid malignancies, Myeloid malignancies**. However, we encourage you to contribute to the other subnetworks, therefore all the surveys are at your disposal in the '**Survey Queue**' button that can be found at the top right of this section.

- Do not forget that only surveys marked as "**Completed**" will be considered for this annual count.
- You can save a draft of your answers by clicking "**Save and Return later**" and come back any time to finalize the submission by clicking "**Submit**".

Please consider that the submission and the edition of the submitted data will be available until the 28th of April 2026 (23:59 CEST).

Thank you so much for your contribution,

ENROL coordination team



Start the survey

FIGURE 2. WELCOMING SECTION

To start entering data you should:

1. Click on the button "**Start the survey**" or select a specific subnetwork survey on the **Survey Queue** section by clicking its corresponding "**Begin survey**" button.

2. Include the requested information.

Fill each field with the corresponding numbers (only numbers are accepted).

VERY IMPORTANT while filling the numeric fields with values:

- **0:** Means that the real number of patients seen for the variable is 0.
- **Empty:** No data for this variable can be provided (no tracking of this patients at your center or your data is not stratified at this level).

3. Select the survey status. Only surveys marked as **“Completed”** in this question will be considered in the analysis. **Therefore, please, select “Completed” when you consider the survey is finalized and no more modifications/entries have to be performed in the survey.**

Please, consider that the following question is crucial for the tracking of your participation in the survey.

Status of the survey

☐ Incomplete
☐ Unverified
☒ **Completed**

reset

Only surveys marked as 'completed' in this section will be considered in the analysis

FIGURE 3. SURVEY STATUS


2.2. Save or Submit data

At the end of each survey the participant is able to:

A. Submit data

Once you have finalized the survey response, you should click on the **“Submit”** button. Automatically:

1. The survey is submitted and appears **“Completed”** * at the **Survey Queue**.

 **Survey Queue**
Get link to my survey queue

Dear Máximo Tartaglia,

In this queue you can find the list of surveys corresponding to all of the diseases subnetworks covered by the ERN - EuroBloodNet.



Status	Survey Title
 Completed	Myeloid malignancies Edit response
 Completed	Lymphoid malignancies Edit response
Begin survey	Red blood cell defects
Begin survey	Bleeding-Coagulation disorders
Begin survey	Bone marrow failure and hematopoietic disorders
Begin survey	Hemochromatosis and other iron related disorders

FIGURE 4. SURVEY QUEUE SECTION

- The participant will be able to access another survey through the **Survey Queue** through the **“Begin survey”** button.
- An e-mail will be sent to the participant, including an extraction of the submitted survey with your answers (PDF format).

** This status is not linked to the last question of the survey: appearing as completed here does not mean that survey status has been marked as “Completed”. It exclusively reflects that the button “Submit” has been pressed.*

B. Save data

The **“Save & Return Later”** button gives the possibility to save the data without submitting. REDCap will recognize the survey as partially completed and the participant will be able to return later to finish it.

An e-mail will be sent to the participant including a link to the partially completed survey.

Your survey responses were saved!

You have chosen to stop the survey for now and return at a later time to complete it. To return to this survey, you will need the survey link to this survey.

Survey link for returning

You have just been sent an email containing a link for continuing the survey. If you do not receive the email soon, please check your Junk Email folder.

Or if you wish, you may continue with this survey again now.

[Continue Survey Now](#)

FIGURE 5. SAVE & RETURN SECTION

2.3. Edit submitted data

Edition of data responses will be possible until the **28th of April 2026** (23:59 CEST).

To edit submitted data from a specific survey, you should:

1. Access the **Survey Queue** section.
2. Select “**Edit response**” button of the survey you wish to update.

Survey Queue [Get link to my survey queue](#)

Dear Máximo Tartaglia,

In this queue you can find the list of surveys corresponding to all of the diseases subnetworks covered by the ERN - EuroBloodNet.

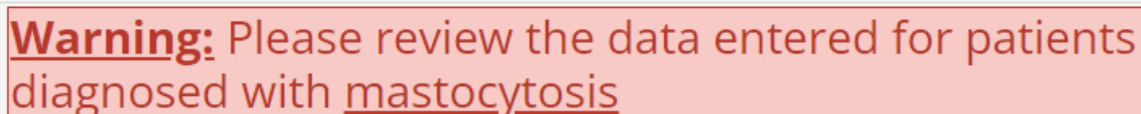
Status	Survey Title
✓ Completed	Myeloid malignancies Edit response
✓ Completed	Lymphoid malignancies Edit response
Begin survey	Red blood cell defects
Begin survey	Bleeding-Coagulation disorders
Begin survey	Bone marrow failure and hematopoietic disorders
Begin survey	Hemochromatosis and other iron related disorders

FIGURE 6. EDIT RESPONSE FROM THE SURVEY QUEUE

3. Data validation in REDCap

3.1. Real time data validation

Real time quality checks have been implemented to ensure that the data submitted is consistent. If the numbers included in the variables of a disease group do not represent the total sum manually entered (e.g. pediatric + adult or female + male), a warning will appear in screen **for the data entry to review the entered data**.



Warning: Please review the data entered for patients diagnosed with mastocytosis

FIGURE 7. PLATFORM WARNING

3.2. Data quality rules

Asynchronous data validation checks will be performed through the **REDCap Data Quality module** by the data monitor. This include the execution of **data quality rules** to find discrepancies in entered data.

Periodic data monitoring will be conducted to review submitted data and identify any data issues while survey's open period.

Once a data issues has been identified, the data monitor will send personalized emails to the designated ENROL EpiBlood data entry to review and address the data issue.