

DELIVERABLE 4.3 ERN-EUROBLOODNET REPOSITORY OF MEMBERS 3

ERN-EuroBloodNet: European Reference Network on Rare Hematological Diseases

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

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Report document

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Short Description

Report on ERN-EuroBloodNet's members' profiles, including data on the HCPs, experts and multidisciplinary team, diseases covered, and core facilities for health provision accessible through [ERN-EuroBloodNet website](#).

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1. INTRODUCTION

CROSS-BORDER HEALTH IN THE FIELD OF RARE HEMATOLOGICAL DISEASES

As is common among Rare Diseases (RDs), expertise in Rare Hematological Diseases (RHDs) is scarce and distributed heterogeneously across the EU. Additionally, there is no accessible repository of human and technical resources available to challenge the difficulties of RHD at the EU or national levels. Consequently, many patients suffer either a delayed diagnosis or remain undiagnosed over time, while it is also well known cases for specific diseases incorrectly diagnosed due to a trend in the awareness of close entities overlapping the clinical manifestations. Additionally, many patients are wrongly monitored resulting in inadequate delivery of healthcare. Furthermore, highly specialized procedures related to curing or monitoring long term complications are not available or properly implemented across EU leading to big Inequalities in access to healthcare.

The Directive 2011/24/EU on Cross-border health provides the keys for the establishment of a referral system for patients and samples in order to ensure equitable access to healthcare across Europe. However, the mapping on the expertise and services available at each MS is basic for the identification of gaps in the system and the establishment of evidence-based patients and cross-border pathways leading to the best healthcare care for each European patient, improvement of health services delivery for RHD across EU and adequate use of resources.

ERN-EUROBLOODNET MAPPING OF EXPERTISE

Expertise on RHD is scarce and heterogeneously distributed across the EU and up to date, there is no accessible repository of human and technical resources available. The ERN-EuroBloodNet mapping of healthcare services in RHDs is the cornerstone for setting the basis for a European model of networking. They rely on a validated identification of experts and Highly specialized procedures (HSP) at both the national and European levels. It also arises the need for cross border health based on existing gaps in certain Member State (MS) for the clinical management of a specific condition while allowing health planning and the better allocation of resources.

The inventory of [ERN-EuroBloodNet repository of members and experts](#) was created for creating a public and accessible repository of the expertise available in the network. ERN-EuroBloodNet inventory is based on Experts, Departments, and Members profiles. Profiles are editable through a set of applications forms allocated in the private area and integrate the ORPHA classification for RHD in its back office, allowing the selection of health professionals' specific areas of expertise as well as for the diseases covered. In addition, a [Disease Search tool](#) has been implemented to exploit the data gathered through the inventory, making the expertise available in the network findable and searchable to the public. Also, RHD disease groups defined were implemented in the back office, as they will become the "tags" for a) the members' reporting of the number of patients and new patients, b) make the expertise in EuroBloodNet searchable and c) classify the contents of the website, i.e. Guidelines, educational material.

ERN-EUROBLOODNET NETWORK ENLARGEMENT AND UPGRADE OF THE REPOSITORY

From their establishment in 2017, ERNs are currently experiencing the enlargement of the number of members of the networks following the call for new ERNs members in 2019. In the case of ERN-EuroBloodNet has is integrating from January 2022 36 new members, resulting in an **expansion of its coverage with a total of 96 members from 18 Member States (MS)**.

Moreover, ERNs systems do not cover the whole EU and EEA area, and therefore devoted efforts have been focused on the integration of Affiliated Partners (APs). APs are not members of the ERNs but are designed to establish links, to contribute to the Networks' activities and benefit from their expertise, facilitating the sharing of knowledge across the EU in those countries where there are no official members established. ERN-EuroBloodNet counts with **7 Affiliated Partners from 6 MS**.

In addition, considering the wide range of prevalences in which RHD disorders are presented, special efforts have to be devoted for the identification of experts on very rare diseases whose highly specialized expertise may still be available in other European centers that are not part of the official ERNs Board of Members or APs and which participation represents a high added value on these precise actions undertaken by the network, as could be their participation on CPMS panels. Accordingly, in the frame of the Connecting EuroBloodNet II (INEA/CEF/ICT/A2018/1816560), the repository was further upgraded for the creation of the Supporting Partners, as expert profiles on very concrete ultra-rare disorders out of Members and APs whose highly specialized expertise is of high added value, while allowing their searchability to participate in CPMS or other very concrete network actions.

Lastly, the collaboration of Patients Organizations is crucial for the running of the Network because they add a high value to actions guaranteeing a patient-centered approach. The ERN-EuroBloodNet **Patients Organizations Supporting Group** is the designation used for those Patients Organizations (Local, National, European or International) that are actively involved in the ERN-EuroBloodNet implementation of specific ongoing projects.

2. OBJECTIVES

ERN-EuroBloodNet established five specific objectives as priorities to be accomplished in the frame of the 5 years of implementation, including the specific objective 1: Improve equal access to highly specialized healthcare delivery for RHD across Europe.

Through this activity ERN-EuroBloodNet aims to build a central repository of reliable sources of information on expertise on RHDs available at both national and European level allowing the:

- a) Identification of needs for cross border health actions based on existing gaps in certain MS for clinical management of a specific condition.
- b) Establishment of new bridges for collaboration not only among expertise available in ERN-EuroBloodNet members but also with other experts out of the ERN coverage.

In this context, the specific objectives of this deliverable are to show the latest actions and results for the expansion and upgrade the ERN-EuroBloodNet repository of members and experts established during the previous periods of network implementation for

- Integration of the new ERN-EuroBloodNet Members and Affiliated Partners ensuring their searchability and visibility
- Creation of Profiles for Patients Organizations Supporting Groups

3. ENLARGEMENT OF ERN-EUROBLOODNET REPOSITORY

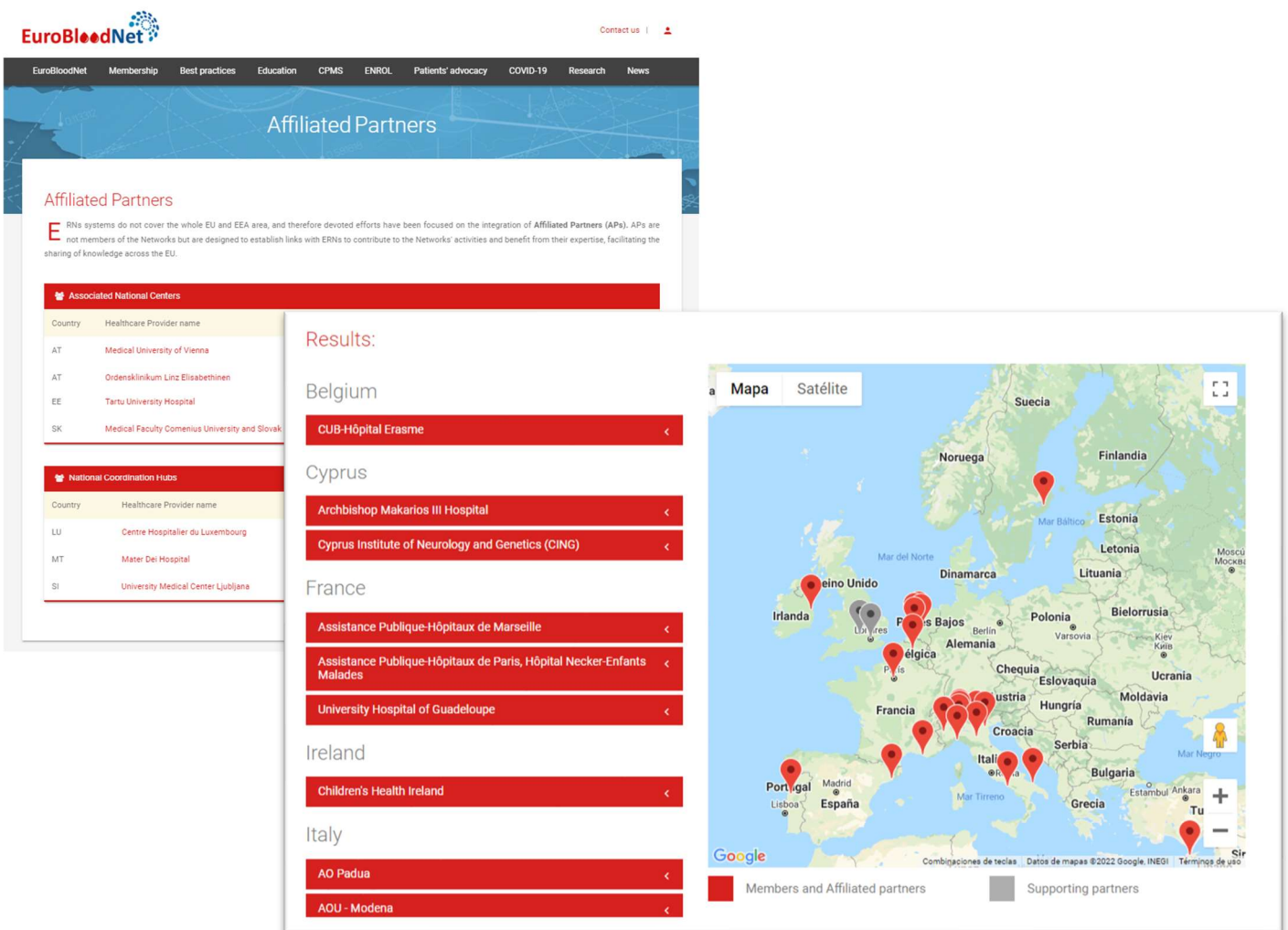
INTEGRATION OF NEW ERN-EUROBLOODNET MEMBERS

The resolution of the Assessment of the call for new ERNs members has allowed the integration of 36 new ERN-EuroBloodNet members. Accordingly, their new profiles for Healthcare providers, Departments and Experts (representatives, substitutes and Multidisciplinary teams) have been created on the [ERN-EuroBloodNet website](#). Further details on the analysis of the repository are developed in section 4 of this deliverable.

CREATION OF PROFILES FOR AFFILIATED PARTNERS

The repository’s back office has been technically upgraded to allow the creation of profiles for Experts, Departments and HCPs profiles for the [Affiliated Partners](#). The design ensures the same structure as for the creation of ERN-EuroBloodNet Members profiles, including the selection of the diseases of expertise based on ORPHA classification.

In addition, these profiles are also findable through [the search tool](#) implemented on the website:



Img 1. Affiliated partners profiles and upgraded search experts tool

CREATION OF PROFILES FOR PATIENTS ORGANIZATIONS SUPPORTING GROUPS

The repository's back office has been technically upgraded to allow the creation of profiles for [Patients Organizations Supporting Groups](#) including the Country, geographical coverage, diseases groups covered by the organization (to be selected from RHD disease groups), Umbrella linked to the organization and links.

The design ensures the same structure as for the creation of ERN-EuroBloodNet Members profiles, including the selection of the diseases of expertise based on ORPHA classification, therefore ensuring an interlink with all the existing profiles with ORPHA classification as common codification element.

The screenshot displays the EuroBloodNet website interface for creating and viewing a 'Patients Organizations supporting group' profile. The top navigation bar includes 'EuroBloodNet', 'Membership', 'Best practices', 'Education', 'CPMS', 'ENROL', 'Patients' advocacy', 'COVID-19', 'Research', and 'News'. The main header features the EuroBloodNet logo and a 'Contact us' link.

The profile page for the 'Lymphoma Coalition' is shown, detailing the following information:

- Organization's name:** Lymphoma Coalition
- Country:** Canada
- Disease groups covered by the organization:**
 - Acute lymphoblastic leukemia
 - Diffuse large B-cell lymphoma, NOS
 - Diffuse large B-cell lymphoma, Other than NOS
 - Follicular lymphoma
 - Hodgkin lymphoma
 - Indolent B-cell lymphomas / Non follicular
 - Mantle cell lymphoma
 - Other aggressive B-cell neoplasms
 - Posttransplant lymphoproliferative disorders (PTLD)
 - Primary cutaneous lymphoma
- Organization's website link:** <https://lymphomacoalition.org>
- Umbrella:** Lymphoma Coalition
- Geographical coverage:** International
- Task forces:**
 - Cutaneous Lymphoma
- Ongoing projects:**
 - Topic On Focus Webinar on Cutaneous Lymphoma for Patients Organizations

Img 2. Patients Organizations supporting group profiles

4. CURRENT STATE OF THE ERN-EUROBLOODNET REPOSITORY

During the analysis presented in this deliverable, a total of 364 have already created their profiles in the ERN-EuroBloodNet directory, including both Members representatives and substitutes and experts invited by them, representing the creation of 94 profiles. The 23 of them belonging to United Kingdom prior members have been maintained in the Supporting Partners section of the website. From the 364 profiles, a total of 182 Members and Affiliated Partners experts profiles have been fully completed.

Aiming to integrate the relevant data introduced so far in the ERN-EuroBloodNet directory of members, the results reported in this deliverable are focused on the profiles completely fulfilled. Results on the number of experts by Member States dealing with oncological or non-oncological subnetworks are shown in table 1. In addition, the specific subnetworks by Member State are detailed in Figure 1.

In line with the results from previous years, Italy, the country with the highest number of Members (34 from 96 members), remains as the country with the highest number of experts in the ERN-EuroBloodNet inventory.

The major subnetwork covered in ERN-EuroBloodNet is the Red Blood Cell disorders as a result of the participation of Italy and Cyprus. This result is logical since Thalassaemia is endemic in the Mediterranean area and the prevalence of this disorder belonging to this subnetwork is very high compared to non-endemic areas.

The increase in the oncological area is principally due to the registered experts from Italy and Portugal. However, the majority of the biggest increase in the Non-Oncological area has been carried on by the Italian experts (from 48 to 60).

MS	Members	Affiliated Partners	Non-Oncological	Oncological
AT	0	2	0	2
BE	10	0	8	3
BU	1	0	1	0
CY	20	0	20	0
CZ	1	0	0	1
DK	0	0	0	0
EE	0	0	0	0
FI	0	0	0	0
FR	35	0	24	12
DE	3	0	0	3
GR	0	0	0	0
HU	0	0	0	0
IE	1	0	1	0
IT	67	0	60	27
LT	2	0	1	1
LU	0	0	0	0
MT	0	0	0	0
NL	16	0	21	3
PL	6	0	0	6
PT	7	0	5	5
SK	0	1	1	0
SI	0	0	0	0
ES	6	0	8	0
SE	4	0	7	0
Total	179	3	157	63

Table 1. Number of experts dealing with non-oncological and oncological subnetworks by country

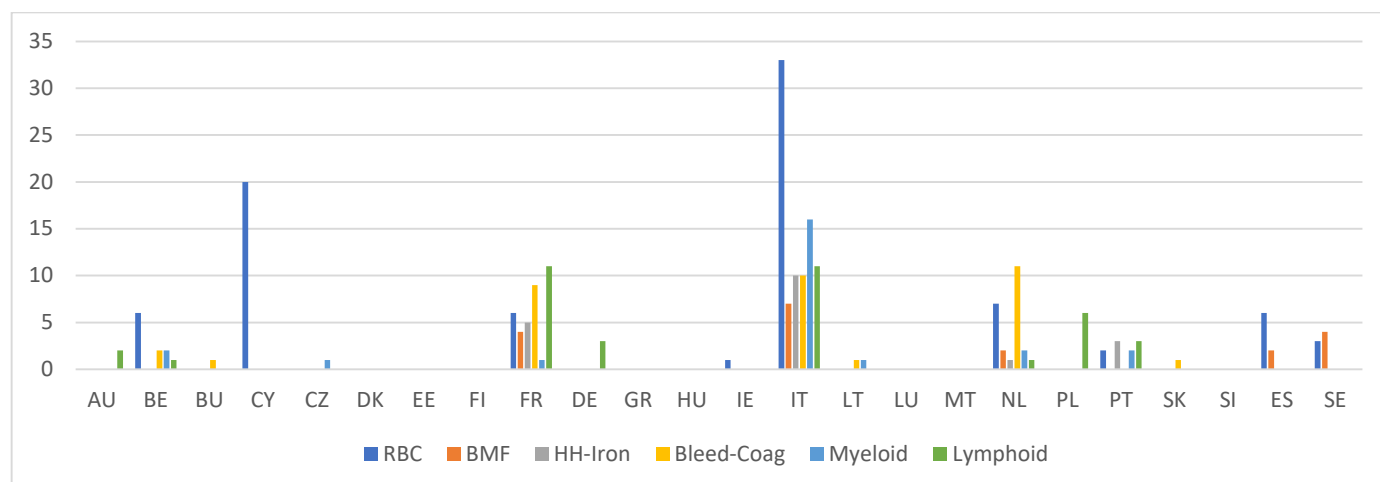


Figure 1. Number of experts by subnetwork and country. Subnetworks: Red blood cell disorders (RBC), bone marrow failures (BMF), Haemochromatosis and iron defects (HH-Iron), bleeding and coagulation (Bleed-Coag), Myeloid malignancies and lymphoid malignancies

On the other hand, the analysis of the area of expertise of the experts fulfilling the profiles shows differences among the oncological and non-oncological hubs (Fig.2)

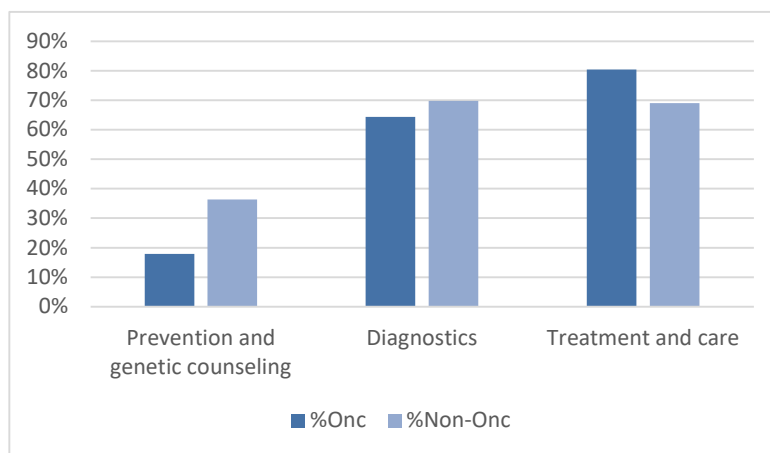


Figure 2 Percentage of experts by their area of expertise and dedicated hub (Oncological (Onc), Non-Oncological (Non-Onc)).

The trends of both hubs are decreasing during this period except for the diagnostic area of the Non-oncological hub which has slightly increased (from 69,8% to 70%). The results obtained on the non-oncological hub point out a slight decrease in the proportion of experts on the treatment and care (from 69,8% to 69%) and the prevention and genetic area (from 38,8% to 36%) too.

When focusing on the oncological diseases, despite the slight decrease in the three areas, the trends have been maintained with regards to data from the previous year in the area of treatment and care, being the vast majority (80%) of the health professionals involved. Regarding the percentage of the experts devoted to the area of diagnostics field has changed, from 67,3 to 64% of and in the prevention and genetic area from 19,8% to 18%.

As has been noticed during the previous periods, the marked preventive character of the non-oncological in comparison to the oncological diseases is manifested, where the percentage of experts on diagnostics represents the 36% of the profiles, while on the oncological hub the proportion is approximately half (18%).

The patients' age coverage is one of the requested points in the registry form in the back office of the website. Figure 3 shows the percentage of experts dealing with children, adults or aged people by hub.

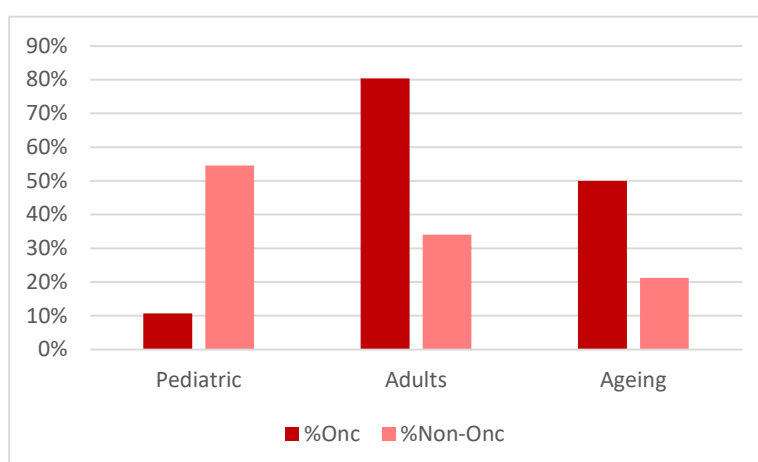


Figure 3 Percentage of experts by the patients' age dealing with and dedicated hub. (Oncological (Onc), Non-Oncological (Non-Onc)).

Although the majority of the results have slightly decreased, the trends of this figure have been maintained with compared to the previous year, highlighting a slight increase in the proportion of experts dealing with Ageing on the oncological hub (from 48,1% to 50% of the experts profiles).

As mentioned in previously deliverables, it is important to point out that the low number of experts from the oncological hub dealing with pediatrics is given since these experts declared to deal with pediatrics, adults and ageing, however, oncological diseases in children are out of the scope of ERN-EuroBloodNet.

5. CONCLUSIONS & NEXT STEPS

ERN-EuroBloodNet mapping of healthcare services in Rare Hematological Diseases (RHDs) is cornerstone for setting the basis for a European model of networking. The European inventory of RHD experts and facilities available at the EU and Member State levels has been based on the implementation of members, healthcare providers, departments and experts profiles, whose edition is available through a set of applications forms that allow the selection of specific diseases of expertise directly from the ORPHA classification.

The mapping could make visible the lack of expertise for a given condition or procedure at the member, MS or EU level, leading to the identification of gaps in the continuing medical education and best practices needs contributing to the continuous shape of the educational plan accordingly, while arising the need for cross border health based on existing gaps in the certain Member States for clinical management of a specific condition while allowing health planning and better allocation of resources.

The European inventory also promotes the collaborations not only among health professionals but also with other European bodies such as the European Medicines Agency (EMA) willing to find experts on specific diseases and/or highly specialized procedures in their country or neighbouring for the provision of best healthcare to patients while enhancing the establishment of bridges for European collaborative projects.

Moreover, the creation of Patients Organizations Supporting Group profiles ensures the visibility of those organizations actively involved in the implementation of ERN-EuroBloodNet ongoing actions. While the structure and back office has been fully implemented, the compilation of the information for the different profiles is ongoing and their publication will be finalized in the next period of implementation.

All in all, thanks to its dynamic structure, the initial mapping of experts and services will be expanded during the next period of ERN-EuroBloodNet implementation for obtaining information on specific highly specialized procedures and members activity linked to ERN monitoring system indicators that will shed light on existing gaps in a certain MS or even at the EU level for the clinical management of a specific condition, allowing the better allocation of resources while setting the basis for the establishment of cross-border referral system for patients and samples.



https://ec.europa.eu/health/ern_en



www.eurobloodnet.eu

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