



## 2.1 ANNUAL DISSEMINATION REPORT

### ERN-EuroBloodNet

### European Reference Network on Rare Hematological Diseases

EUROPEAN REFERENCE NETWORKS  
FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

# Share. Care. Cure.



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## DOCUMENT INFORMATION

### 2.1 ANNUAL DISSEMINATION REPORT

Report Document

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Short Description

Dissemination report including all the activities done for increasing the critical mass of stakeholders and target groups involved.

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## 1. INTRODUCTION

The design and implementation of a robust communication strategy and plan is cornerstone to creating a critical mass of interests necessary for the upgrading of services provided by the experts and expert centres included in ERN-EuroBloodNet, and to increase public awareness of rare hematological diseases (RHD) and of network goals and achievements.

The bidirectional communication of the network requires permanent contacts between the board of ERN-EuroBloodNet and different target groups including a) National and EU health authorities and policy makers b) Healthcare Providers, universities and research centres c) Scientific and national bodies at the national, EU level and international d) Patients' associations, patients and relatives.

Liaison with third parties outside Europe are also promoted since this will add value to the network by enhancing the development and use of registries as well as disseminating information on RHD in neighbouring countries. Both European Hematology Association (EHA) and EURORDIS Rare Disease Europe have links outside of EU that will be informed regularly and invited to dialogue through the communication tools of ERN-EuroBloodNet. This provides a means to strengthen networking and international collaborations, and ensure sustainability of the network.

ERN-EuroBloodNet Dissemination strategy was described in the Dissemination plan defined during the first year of the network aiming to set the basis for the overall strategy to promote and expand the knowledge of ERN-EuroBloodNet to the different stakeholders already identified for the five years of implementation, including five main objectives to be achieved:

- To define and establish a dissemination plan including creation of the dissemination material (ie Leaflets, slide presentations...) and creation of a Dynamic Stakeholders Directory
- To develop and stimulate ERN-EuroBloodNet social media channels as the main powerful tools for dissemination, including ERN-EuroBloodNet website, ERN Collaborative platform, newsletter and social networks.
- To promote collaboration agreements with third parties: other ERNs, European Research Infrastructures Consortiums.
- To increase awareness and knowledge on RHD through the organization of European Symposia for health professionals and patients.
- To disseminate reports on ERN-EuroBloodNet outcomes via website and ERN Collaborative platform to improve clinical care and increase public awareness, together with a final publication.

This document describes the activities implemented as part of Work Package 2 "Dissemination" aiming to promote and to expand the knowledge of ERN-EuroBloodNet among the Health and legal authorities, scientific community, patients' organizations and public in general.

## 2. OBJECTIVES

ERN-EuroBloodNet's dissemination includes all the activities aiming to expand knowledge of the ERN in RHDs, its website and its activities and services in order to get the necessary critical mass to make the network fully successful and ensure its long-term sustainability.

Specific objectives for the third year of implementation of ERN-EuroBloodNet are:

1. To exploit the ERN-EuroBloodNet Repository of experts and services
2. To increase awareness on ERN-EuroBloodNet actions and results by the update and upgrade of the ERN-EuroBloodNet's website, stimulation of social media channels and participation in RHD events
3. To promote collaboration agreements with third parties and strengthen the existing ones

### 3. TASKS

## TASK 1. EXPLOITATION OF THE ERN-EUROBLOODNET REPOSITORY OF EXPERTS AND SERVICES

The inventory of ERN-EuroBloodNet members and experts is based on the implementation of members, healthcare providers, departments and experts profiles, gathering the essential information on patients activity and healthcare services offered for a) identifying gaps on services and expertise on the different fields across Europe and b) showing publicly useful information not only for patients and health professionals but also for policy makers, regulatory bodies as EMA and organisms in charge of health technology assessment.

ERN-EuroBloodNet Members, departments and experts' database and public profiles have been designed as dynamic tool allowing both its continuously edition directly by the experts and its expansion by the inclusion of new members in the future stages.

The inventory has been envisaged to interrelate all the items providing huge possibilities for the disease or group of diseases target data analysis while boosting search engines, as the already implemented [Disease Search tool](#).

In this context, special efforts have been focussed during this period to upgrade the repository to allow:

- Monitoring members' activity based on the gathering of Key Performance Indicators (KPIs)
- Mapping availability of HSPs considered as essential for the delivery of best healthcare.

Methodology tasks implemented for the upgrade are fully detailed at **Deliverable 4.1 ERN-EuroBloodNet Repository of members**

Further exploitation of data gathered will allow:

- ✓ Identification of experts (evidence-based at national and European level) for experts boards within EuroBloodNet actions or relations with other bodies i.e. EHA, ESH, EMA, bodies in charge of Health Technology Assessment
- ✓ Better allocation of resources / Health planning
- ✓ Better access to healthcare

## TASK 2. UPGRADE AND DEVELOPMENT OF NEW ERN-EUROBLOODNET COMMUNICATION TOOLS AND CHANNELS

### 2.1 UPDATE AND CREATION OF NEW ERN-EUROBLOODNET COMMUNICATION MATERIAL ERN-EUROBLOODNET DELEGATE PACK

Taking advantage of the concentration of major ERN-EuroBloodNet stakeholders during the annual meeting of the network, a pack for dissemination was produced for its distribution among members, affiliated partners, patients representatives and other major contributors to the network implementation attending the meeting. The dissemination pack included computer bags, notebooks, pens, headsets and dissemination material generated for the network (leaflet, flyer ...).

#### POSTER AND PPT

A new DINA0 Poster template presenting the ongoing projects implemented by the network by transversal fields of action (TFA) was produced aiming to present the main concrete areas of active action in the network. The poster was designed to include for each of the TFA a) Challenges encountered, b) Actions so far, and c) results. Contacts for the coordination team are also provided. European Commission rules in terms of visibility have been fully ensured.

Presentation slides are constantly evolving depending on the audience or the subject of the meetings. Having an extensive reference presentation is useful in order to use the most relevant parts for a given audience in every talk where ERN-EuroBloodNet is introduced.

An updated power point presentation on ERN-EuroBloodNet ongoing projects was presented and shared through the ERN Collaborative Platform after the Board of the Network meeting in order to facilitate the dissemination of the network to a wide range of public by summarizing most relevant challenges and achievements. Different from the general presentation produced during the second year of the network, this power point includes 16 slides focussed on the current active lines of work under the each of the specific TFAs.

Additionally it is important to mention that members are welcomed to contact Coordination team in case specific information or slides on the specific actions are required to be presented in their talks.

## NOTEBOOKS FOR EDUCATIONAL ACTIONS

A number of educational actions have been performed during the third year of ERN-EuroBloodNet implementation targeting both, patients and health professionals. In this context, dedicated notebooks have been designed and produced in order to be provided to the beneficiaries of such courses given the usefulness of this material during the course.

## 2.2 ERN-EUROBLOODNET COMMUNICATION TOOLS

### NEWSLETTER

ERN-EuroBloodNet newsletter aims to transmit stakeholders the most relevant RHD news while keeping them updated with the main achievements of ERN-EuroBloodNet, maximizing the impact of ERN-EuroBloodNet activities. A first version of the ERN-EuroBloodNet newsletter was designed during the 2nd year of implementation. In this period, final improvements on its designed were performed before final release in October 2019. The final design of the newsletter includes:

- Introductory header with ERN-EuroBloodNet logo and Month of newsletter
- Two emphasized pieces of news, including title, subtitle, picture and link to the piece of news
- Unlimited number of pieces of news in a smaller size, including title, subtitle, picture and link to the piece of news
- Footer with ERN-EuroBloodNet logo and EC recognition
- Privacy policy disclaimer, including the link to unsubscribe



### TWITTER

ERN-EuroBloodNet twitter account was created during the first year of the Network in order to increase the impact of the messages launched by the network.

### NEW EUROBLOODNET SOCIAL CHANNELS: FACEBOOK AND LINKEDIN

Taking into consideration the huge impact of social networks on the daily life and with the aim of reaching a broader audience, ERN-EuroBloodNet has increased its presence in these communication channels through two of the major social networks: Facebook and LinkedIn.

### REPORT ON 3RD EUROBLOODNET BOARD OF NETWORK MEETING

The 3rd EuroBloodNet Board of Network meeting was held last 13 and 14 November in Vall d'Hebron University Hospital, Barcelona, with the participation of more than 80 attendees. The audience included member representatives, patients' organizations, candidates for new members, affiliated partners and collaborating stakeholders as the European Hematology Association (EHA), the European School of Hematology (ESH) or International Quality Expertise (UKNEQAS).

In addition to plenary sessions, on this occasion the meeting counted with two Parallel Sessions where the main actions and results implemented by the network were presented by the projects coordinators finalizing with key questions to be discussed by the audience divided into areas of expertise.

The meeting provided the whole overview of the status of the ongoing projects undertaken by the network while enhanced discussion on important questions risen during the Parallel sessions, leading to a) reaching consensus for upcoming next steps on the methodological approach for the ongoing projects, while b) creation of new projects proposed to be implemented in needs identified.

Major outcomes were distributed by mail to ERN-EuroBloodNet stakeholders, including the full report of the meeting outcomes for further details and links to the ERN Collaborative platform for downloading the slides presentations.



## 2.3 EXPANSION OF ERN-EUROBLOODNET WEBSITE

ERN-EuroBloodNet website has become the main tool of dissemination of the network since its release last July 2017, providing the skeleton of the complex structure that ERN-EuroBloodNet represents by endorsing specific dedicated sections to the all the activities and tools developed by the networks while ensuring interoperability with other platforms.

ERN-EuroBloodNet website has been conceived as the on-line platform that provides not only the door of access to ERN-EuroBloodNet dynamic and public inventory of members and experts but also to the main tools developed and implemented during the running time of the network.

In this context, ERN-EuroBloodNet website can be understood as two-side online platform with two main objectives:

- ERN-EuroBloodNet website as the main tool for dissemination of the goals and achievements to boost public awareness of the network.
- ERN-EuroBloodNet website as the infrastructure (web portal and database) for accessing the Inventory of ERN-EuroBloodNet members and experts profiles

New sections and specific target-actions engines have been implemented in this period for the exploitation of the data collected while keeping the website in an evolving environment attending to the network's need.

## 2.4 PROMOTION OF THE USE OF THE ERN COLLABORATIVE PLATFORM

The platform developed by the EC provides huge possibilities for an easy communication and sharing of documents among ERN-EuroBloodNet members. Its use have been promoted in this period of the network.

## 2.5 DISSEMINATION AT EUROPEAN RARE DISEASES MEETINGS AND WORKSHOPS

Although Online and virtual relations make cooperation easier, the participation in physical events still offers good opportunities to share messages and ideas. All the activities developed by ERN-EuroBloodNet members have been reported to coordination team.

# TASK 3 – RELATIONS WITH THIRD PARTIES

## 3.1 PROMOTION OF COLLABORATION AGREEMENTS WITH THIRD PARTIES

In order to create a real network it is essential to create synergies with other ERNs, projects and initiatives working towards objectives complementary to those of ERN-EuroBloodNet. Links for collaborative agreements have been already established and consolidated during this second year, eg. Orphanet, EURORDIS, patients' associations and National and International Scientific organisations.

## 3.2 PROMOTION OF RELATIONS WITH NATIONAL SCIENTIFIC SOCIETIES OF HEMATOLOGY

National Scientific Societies of Haematology in Europe as major channels of the hematology stakeholders at the national level.

In an effort to increase the outreach of the ERN-EuroBloodNet activities and results of the network, a list of National Societies of Hematology Associations have been created in order to be approached, including the following details:

- Country
- Subnetwork/RHD
- Coverage of Pediatric/ Adults/Both
- Name of Society
- Contact
- Website
- Contact Person and mail
- Post address



## 4. RESULTS

### LINKED TO TASK 1. EXPLOITATION OF THE ERN-EUROBLOODNET REPOSITORY OF EXPERTS AND SERVICES

#### 1.1 RARE HEMATOLOGICAL DISEASES - DISEASE GROUPS DEFINITIONS

A total of 70 RHD-DG has been identified and are currently under revision for final approval, as follows:

- Red blood cell defects: 10 disease groups encompassing 59 disorders
- Bone marrow failure and hematopoietic disorders: 12 disease groups encompassing 42 disorders
- HH and other rare genetic disorders of iron metabolism and heme synthesis: 11 disease groups encompassing 29 disorders
- Rare bleeding-coagulation disorders and related diseases: 9 disease groups encompassing 70 disorders
- Lymphoid malignancies: 19 disease groups encompassing 98 disorders
- Myeloid malignancies: 9 disease groups

RHD-DGs and disorders included under each group are available at [Cross-Border Health section](#) at ERN-EuroBloodNet website.

RHD-DGs will become the central piece of the repository for the reporting of KPIs, accordingly has been already implemented at the inventory's back office.

#### 1.2 IMPLEMENTATION OF "STATISTICS" SECTION FOR REPORTING KPIs

The section "Statistics" has been implemented in the Experts profiles to directly report: the period of monitoring, disease group, number of patients and diagnostic procedures.

In order to facilitate the reporting, it is only possible to include the numbers for the subnetwork to which the expert is linked. In addition, the selection of the RHD-DGs to be reported is selectable from a list filtered by the given subnetwork.

The "Statistics" section is already programmed and is currently being tested by the coordination team for potential improvements on its visualization.

### LINKED TO TASK 2. EXPLOITATION, UPGRADE AND DEVELOPMENT OF NEW ERN-EUROBLOODNET COMMUNICATION TOOLS AND CHANNELS

#### 2.1 UPDATE AND CREATION OF NEW ERN-EUROBLOODNET COMMUNICATION MATERIAL

ERN-EuroBloodNet delegate pack was created for its delivery on the 3rd EuroBloodNet Board of the Network meeting, held 14th and 15th November 2019 in Vall d'Hebron University Hospital, Barcelona. A total of 100 computer bags with ERN-EuroBloodNet logo were designed and filled with the following material produced in the previous phase of the network implementation:

- ERN-EuroBloodNet pen
- ERN-EuroBloodNet notebook
- ERN-EuroBloodNet leaflet and flyer
- Headsets

Also 100 lanyards were newly designed and produced for the event, including the ERN-EuroBloodNet website, the general logo of the ERNs and the dedicated for ERN-EuroBloodNet communication purposes.

In addition, translated leaflets and flyers produced during the 2nd year of implementation were available on the tables at the entry of the conference room.

On the other hand, new ERN-EuroBloodNet poster and presentations have been distributed via the ERN Collaborative platform and adapted according to the specific needs of the communication events.

Dedicated notebooks for educational actions were produced for the following events:

- Sickle Cell Disease Research Prioritisation Workshop at the Annual Scientific Conference on Sickle Cell and Thalassaemia, ASCAT 2019
- Preceptorships on Aplastic Anaemia and Paroxysmal Nocturnal Hemoglobinuria in adult and pediatric patients, 2019

In the notebooks, a general description of ERN-EuroBloodNet was included, together with the objectives of the specific action and also agenda for the course. ERN-EuroBloodNet logo was included.

## 2.2 ERN-EUROBLOODNET MONTHLY NEWSLETTER

ERN-EuroBloodNet Newsletter was launched in October 2019 and is released on monthly basis. All editions are available at [ERN-EuroBloodNet website dedicated section](#):

- [October 2019](#)
- [November 2019](#)
- [December 2019](#)
- [January 2020](#)
- [February 2020](#)

The newsletter is sent via the General Data Protection Regulation-compliant email platform [MailerLite](#).

A total of 328 subscribers receives the newsletter, including health professionals with profile created in ERN-EuroBloodNet repository of members and experts, and the new subscribers via web at the dedicated section of [ERN-EuroBloodNet website](#).

Statistics of the newsletters campaigns are the following (February newsletter sent 27/02/2020, accordingly not included in the analysis below):

	Total emails sent	Opened	Open rate	Clicked	Click rate
Newsletter October 2019	327	96	29.63%	12	3.70%
Newsletter November 2019	328	97	29.75%	21	6.44%
Newsletter December 2019	328	101	30.98%	14	4.29%
Newsletter January 2020	329	98	29.79%	13	3.95%

Considering the generally accepted measures for an email campaign success (source: [Campaign Monitor](#)):

- [Average email open rate should be between 15-25%.](#)
- [Average click-through rate should be about 2.5%.](#)

Accordingly, in general terms Newsletters campaigns can be defined as successful. While an increase rate is observed for the opening of the newsletter, it is remarkable the number of higher clicks is presented at the edition of November 2019, where the piece of news with higher number of clicks was the related to the [ERN-EuroBloodNet Board of Network meeting](#).

## 2.3 ERN-EUROBLOODNET SOCIAL NETWORKS: TWITTER, FACEBOOK AND LINKEDIN

@ERN-EuroBloodNet Twitter account registers more than 1000 Tweets, 700 followers (233 more than last year) and 166 followed. Active interactions are given among the rest of ERNs, EU Health, projects as EJP on RDs, ELIXIR or RD-Connect, patients' associations as EURORDIS or Myeloma Europe, scientific associations as EHA or ESH (European School of Hematology) among many others.

In addition, the following two new social networks have been launched in February 2020:

- [ERN-EuroBloodNet Facebook](#) as one of the major social networks mainly addressing general audience
- [ERN-EuroBloodNet LinkedIn](#) as one of the major social networks connecting professionals



A dedicated piece of news on the launching of the new social networks is available at:

- [ERN-EuroBloodNet new social networks! Follow us on Facebook and LinkedIn!](#)

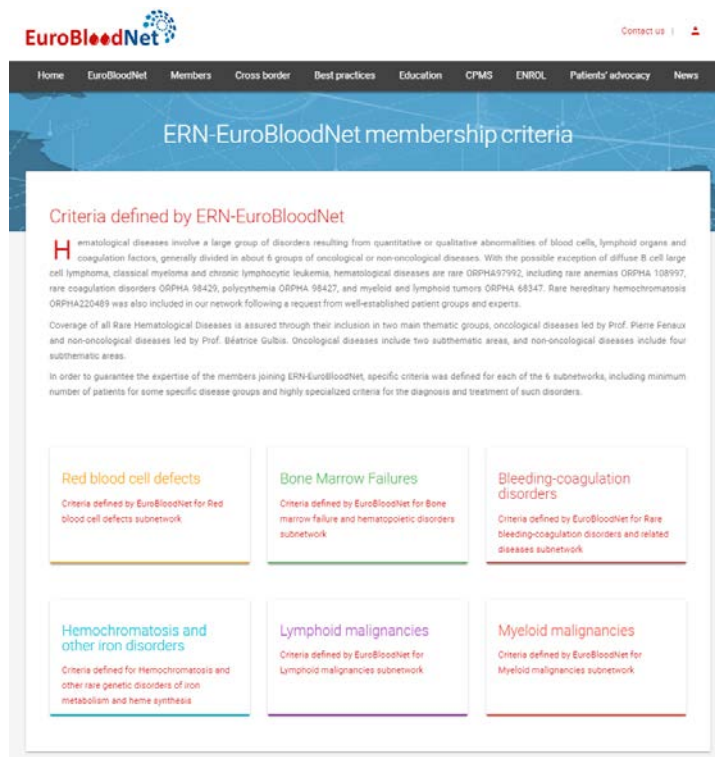
## 2.4 NEW SECTIONS ON THE ERN-EUROBLOODNET WEBSITE

### MEMBERSHIP CRITERIA AT THE MEMBERS' SECTION

As for other rare diseases, one of the major challenges for the optimum management of RHD is the requirement of highly specialized procedures for their diagnosis, treatment or follow up. Given the highly specialization of such procedures or services, it is common that most of them are not widely available in all countries and thus, where cross border health (CBH) actions are required.

The mapping of the highly specialized procedures and services in every country is essential to analyse the needs of CBH and one of the major aims to be achieved by the network. While the exhaustive mapping will be performed through the inventory of members and services in next stages of implementation, some useful information was gathered through the members applications to join the network in 2016, when the subnetworks criteria were defined to join ERN-EuroBloodNet.

In this context, the [Membership criteria section](#) has been released at the website with the Member section, for the inclusion of the criteria defined by the network for the six subnetworks, being available not only new potential members who were willing to apply the new call 2019, but also to general public ensuring transparency in ERN-EuroBloodNet criteria for members.



### CROSS BORDER HEALTH SECTION

ERN-EuroBloodNet aims to build a central repository of reliable sources of information on expertise available at both national and European level in RHDs. To this aim, RHDs have been grouped into disease or disease groups (RHD-DGs) based on the analysis of codification schemes (ORPHA and ICD) for definition of rare diseases. In this context, efforts have been performed for the establishment of RHD-DG in order to become the center piece of the ERN-EuroBloodNet central repository for:

- Mapping of experts: disease coverage
- Mapping of patients and HSPs through members' reporting on KPIs: number of patients/new patients and number of procedures HSPs
- Classify the contents of the website, i.e. Guidelines, educational material.

The first version of the RHD-DG and diseases included (currently under final revision), as well as a brief explanation of the methodology followed for their definition are available at the [Cross-Border health section](#).

### BEST PRACTICES SECTION

#### GUIDELINES AND RECOMMENDATIONS

One of the key objectives established by ERN-EuroBloodNet is to foster best practice sharing in RHD by creating a comprehensive public repository of reliable evidence based guidelines, ranging from prevention, diagnostic tests and treatments to the organisation of patient-centred management in multidisciplinary teams.

The main actions devoted to this objective has been detailed in [Guidelines and Recommendations section](#), including the number of documents compiled and the exercise performed for their classification. The [repository of Clinical Practice Guidelines and other Clinical Decision Making Tools](#) classified based on Quality Domains are available at the dedicated section.

#### EXTERNAL QUALITY ASSESSMENT

The [External Quality Assessment section](#) describes the a collaboration established with UKNEQAS for a) the analysis of the state of the art of External Quality Assessment for the RHDs diagnosis and b) promote the establishment of schemes for RHD where gaps are identified.

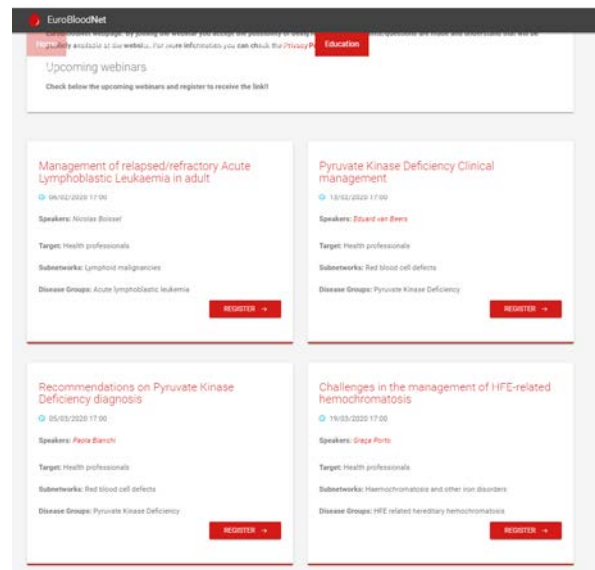
## EDUCATION SECTION

### WEBINARS

ERN-EuroBloodNet Thursdays webinars has been launched at the beginning of 2020 with the aim of promoting the interest on very innovative topics in order to stress among health professionals the cutting-edge advances in the field of Rare Hematological Diseases. Webinars are mainly addressed on very rare diseases, complex disorders, highly specialized procedures and implementation of guidelines. At the same time, webinars' programs that are specifically addressed to patients intends to increase the awareness on a specific rare hematological disease among patients' advocates and patients associations.

[Webinars section](#) includes an overall of the ERN-EuroBloodNet Thursdays webinars program, and dedicated boxes with the details of each of the next webinars, including a) Topic, b) date, c) speaker, d) scope and e) link to registration.

Past webinars recording and presentations are also available at the [Past webinars section](#).



### PRECEPTORSHIPS

ERN-EuroBloodNet is endorsing three preceptorships held in ERN-EuroBloodNet highly specialized centers for Aplastic Anaemia and Paroxysmal Nocturnal Hemoglobinuria with the objective to provide applicants with the fundamental tools for a correct diagnostic and treatment approach to bone marrow failures in children, adolescents and adult patients.

[Preceptorships section](#) has been created to provide an overview of need for this action, a brief description of the 3 available programs (Paris, Naples and Genova) including coordinators and teachers, procedure to apply (in the period of the opened call) and criteria. Once the call for participants was closed, the number of students in each hosting programme was also announced.

Upcoming program will be focused on Sickle Cell Disease. A specific subsection will be created soon for further details on the preceptorships, procedures to apply and criteria.

## CLINICAL PATIENT MANAGEMENT SYSTEM (CPMS) SECTION

In collaboration with CEF Grant Connecting ERN-EuroBloodNet (2017-FR-IA-0095), ERN-EuroBloodNet CPMS section was created in ERN-EuroBloodNet website for users to retrieve support information on three different CPMS related sections:

### ABOUT CPMS

[About CPMS section](#) includes General information on the objectives and utilities of the platform and ERN-EuroBloodNet helpdesk. This section includes link to other related website sections (“How to use the CPMS”, “Find experts for CPMS panels”) as well as direct link to the CPMS.

### HOW TO USE THE CPMS

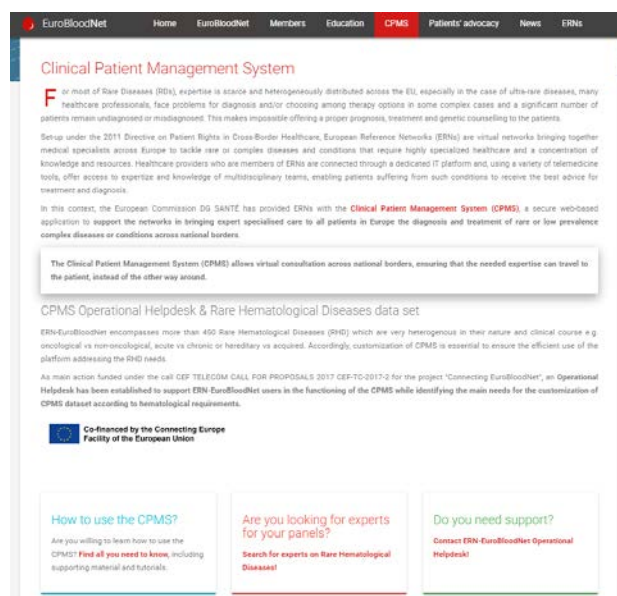
[How to use the CPMS section](#) includes practical information for the use of the CPMS:

- Frequently Asked Questions: Create CPMS account, how to open a panel...
- Supporting material: short guides and video tutorials
- Other useful links

### FIND EXPERTS FOR PANELS

[Find experts for panels section](#) explains the relevance of the ERN-EuroBloodNet inventory of members and experts and the importance of making expertise searchable for the invitation of experts to contribute to the CPMS panels. Direct link to the disease search tool is included.

The EU emblem and acknowledgement “Co-financed by the Connecting Europe Facility of the European Union” were included in the three subsections of the CPMS.





## EUROPEAN RARE BLOOD DISORDERS PLATFORM (ENROL) SECTION

ENROL proposal was submitted under the Call for proposals HP-PJ-2019 on Rare disease registries for the European Reference Networks to become the umbrella for both new and already existing registries on RHD, and has been successfully granted on January 2020.

[ENROL section](#) offers an overview of the aims of the platform and structure until the official launch of the project.

### NEWSLETTER SECTION

[Newsletter subsection](#) has been endorsed under the News section, in order to publish all the monthly newsletter sent while offering the possibility of subscribing.



## 2.5 PROMOTION OF THE USE OF THE ERN COLLABORATIVE PLATFORM

The [ERN-EuroBloodNet dedicated section in the ERN Collaborative Platform](#) has been used in order to share with ERN-EuroBloodNet members the following documents:

- ERN-EuroBloodNet 2nd year of implementation final report, including Deliverables submitted to Chafea
- Slides presented at the EuroBloodNet interactive session at European Hematology Association (EHA) congress, June 13 - 16, 2019, Amsterdam
- Report on outcomes and Slides presented during the 3rd Board of the Network meeting hold the 13-14 November in Barcelona

A total of 54 ERN-EuroBloodNet users are active in the ECP.

## 2.6 DISSEMINATION IN EUROPEAN RARE DISEASES MEETINGS AND WORKSHOPS

ERN-EuroBloodNet members are devoted to spread the messages and services of the network in every forum that might be relevant to strengthen the network. Meetings on RHDs are frequent around Europe and the ERN-EuroBloodNet members work to have a presence in the most relevant ones. Most relevant events with an active participation of ERN-EuroBloodNet have been during this period:

- 2019 International Conference of the Korean Society of Hematology meeting, March 14th 2019, "EuroBloodNet activities" by María del Mar Mañú Pereira
- Italian National Meeting at Hospital Policlinico Milano, March 29th 2019, "Establishment of an European Network of Sickle Cell Disease Patients Organization" by Mariangela Pellegrini
- Workshop on Assessment of a European Expert Network on communicable diseases and other rare pathologies in the context of Mobility and Globalisation, Barcelona, April 8th 2019, "Improving registries and clinical trials for rare diseases" by María del Mar Mañú Pereira
- Belgian Hematology Society - Red Blood Cell Committee, May 9th 2019, "Telemedicine on the European platform" by Fahed Ahssini (CPMS Helpdesk)
- EURORDIS membership meeting, Romania, May 17th 2019, "Establishment of an European Network of Sickle Cell Disease Patients Organization, as ERN Best Practice Model for patients involvement." by Loris Bruneta (ePAG)
- European Hematology Association (EHA) congress, June 13 - 16, 2019, Amsterdam
  - EuroBloodNet interactive session provided by the coordinators of the ongoing projects
  - Presentation of the network at the Myelodysplastic diseases EHA working group, by Scientific Director, Maria del Mar Mañú
  - Dedicated booth for ERN-EuroBloodNet dissemination, Victoria Gutierrez and Mariangella Pellegrini
- 8th National day of la Filière de Santé MCGRE, Paris, June 28th 2019 "EuroBloodNet actions on research" by Pierre Fenaux

- Meeting Regional Government Authorities at Gaslini Hospital, July 3rd 2019 " EuroBloodNet aims and achievements" by Carlo Dufour (member representative)
- European Cancer Summit, Brussels, September 13th 2019 " Cancer treatment across borders ERN-EuroBloodNet perspective" by Béatrice Gulbis
- Innovation Bootcamp in Rare Disease, Brussels, November 5th 2019, " EuroBloodNet: providing specialized care for patients with rare hematological diseases across Europe" by Béatrice Gulbis
- New perspectives in the approach of children with hematological diseases, Barcelona, November 5th 2019, Barcelona, " ERN-Eurobloodnet initiatives for sickle cell disease" by Victoria Gutierrez Valle
- EHA Red cells and iron Scientific Working Group, Madrid, 7th November 2019, "EuroBloodNet three years of experience" by Patricia Aguilar Martinez (member representative and TFA Education coordinator)
- Italian meeting for European Reference Networks on Rare Disease Day, February 22nd 2020, Pisa, " ERN-EuroBloodNet actions" by Antonella Meloni (member)

## LINKED TO TASK 3. RELATIONS WITH THIRD PARTIES

### 3.1 PROMOTION OF COLLABORATION AGREEMENTS WITH THIRD PARTIES

#### EUROPEAN COMMISSION AND ERNs COORDINATORS GROUP

After the official approval for the 24 ERNs, a supra level group of coordinators was created for facilitating the gathering of different needs on common issues across the ERNs, sharing different points of view and facilitate the bidirectional communication with the EC.

The ERNs coordinators groups (ERNs CG) is formed by the 24 coordinators of ERNs, and during the third year it works under the coordination of Prof Irene Mathijssen (ERN CRANIO).

ERN-EuroBloodNet has been present in all the ERNs CGs meetings organized by the EC aiming to update coordinators in the main issues concerning the operational management of the networks. ERN CGs meetings organized in this period have been the following:

- 7th meeting of the ERNs CG, 25th March 2019 in Brussels - Attended by ERN Scientific Director, Maria del Mar Mañú.
- 8th meeting of the ERNs CG, 24th June 2019, Brussels - Attended by ERN IT and Dissemination manager, Victoria Gutierrez Valle
- 9th meeting of the ERNs CG, 14th November 2019, Brussels – Attended by Eduard van Beers as WG on Research representative.

In order to address the different frames of action, 6 Working Groups (WG) were established, where each ERN could participate, through their coordinators or any of their members, up to 3 WG. Given their high level of implication and constant increase of activity, during this period some of the representatives of the WGs for EuroBloodNet were changed. Accordingly:

- WG on Research presents two major subgroups, namely a) the registries represented by Maria del Mar Mañú Pereira, Eduard van Beers and Matteo della Porta and b) for basic and translational research, EuroBloodNet is represented by Richard van Beers, Paola Bianchi and Eduard van Beers.
- WG on Cross border health and brexit is represented by Raffaella Colombatti
- WG on Knowledge generation, including Taxonomy of Clinical Practice Guidelines and other related documents, represented by Maria del Mar Mañú, Luca Malcovati and Achille Iolascon
- WG on Monitoring, has been recently joined by ERN-EuroBloodNet with the participation of María del Mar Mañú and Victoria Gutierrez Valle.

ERN-EuroBloodNet has been present in all the ERNs WGs dedicated meetings, including in this period have been the following:

- WG Research: 14th November 2019, Brussels attended by Eduard van Beers
- WG Knowledge generation: 6th February 2020, Brussels attended by Luca Malcovati

#### ERNS ON RARE CANCERS

Tackling cancer is of fundamental importance for Europe's future. By 2035, there will be a doubling of cancer cases and an estimated 40% of the population will face cancer at some point in their lives. However, at the same time 40% of all cancers can be prevented if we implement what we know already. With these numbers, the European Commissioner for Health and Food Safety has launched Europe's Cancer Plan proposing actions at every key stage of the disease: prevention (lifestyle, pollution, vaccination), diagnosis, treatment and survivorship.

Europe's Cancer Plan was launched on a dedicated Conference on 4 February - World Cancer Day at the European Parliament in Brussels, supported by the MEPs Against Cancer Interest Group. This event aimed to demonstrate the EU's strong commitment to fighting cancer and to harness the collective power for positive change.

The half day event brought together a range of stakeholders including political leaders, representatives from international organisations, health ministries, leading academics, scientists and health professionals, the private sector and NGOs as well as cancer patients and survivors, who shared their personal testimonials.

ERNs tackling rare cancers (ERN-Paedcan, ERN-Genturis, ERN-Euracan and ERN-EuroBloodNet) were invited to the event. ERN-EuroBloodNet coordinator Prof Fenaux, ERN Manager Mariangela Pellegrini, and e-Learning manager Julia Zajac attended in representation of the network. Europe's Cancer Plan will strengthen collaboration among the four ERNs devoted to rare cancers.

A dedicated piece of news on the event is available:

- [Europe's Beating Cancer Plan was presented at the European Parliament on World Cancer Day](#)

## ORPHANET

Orphanet is the reference portal for information on rare diseases and orphan drugs, for all audiences aiming to help the improvement of the diagnosis, care and treatment of patients with rare diseases. ENERCA project was previously in tight collaboration with Orphanet for the preparation of the International Classification of Rare Diseases (IDC+11).

ERN-EuroBloodNet has established a collaboration for the implementation of ORPHA classification for RHD at the back office of ERN-EuroBloodNet website prior revision of the classifications by subnetworks coordinators. Collaboration will be strengthened with the aim of contributing to the improvement of the Orphanet nomenclature.

## EURORDIS

EURORDIS represents more than 270 rare disease organisations from 32 countries, 19 of which are EU member states, and thereby reflects the voice of an estimated 30 million patients affected by rare diseases in the EU. One of its most important activities was the promotion of national centres of expertise and European Reference Networks.

ERN-EuroBloodNet has strengthened its relationships with patient associations through a close collaboration of EURORDIS ePAGs. In addition, the generation of contents for social networks consolidates and creates new contacts with patients through these organizations.

ERN-EuroBloodNet has also collaborated in the dissemination of the activities organized by for the Annual Rare Diseases Day. The dissemination has been mainly done through ERN-EuroBloodNet website and twitter by posting news and contributing to the Rare Disease Day movement.

- [Nominations for the EURORDIS Black Pearl Awards 2020 are now open!](#)
- [Congratulations to the winners of EURORDIS Black Pearl Awards 2020!](#)
- [Rare Disease Day 2020: One month to go! Get involved!](#)

ERN-EuroBloodNet will be also present at the biennial European Conference on Rare Diseases and Orphan Products organized by EURORDIS that will be held on 15-16 May 2020 in Stockholm. ERN Manager, Mariangella Pellegrini will attend representing EuroBloodNet. A piece of news for the dissemination of the event has also been published:

- [European Conference on Rare Diseases & Orphan Products \(ECDR\) will take place 15-16 May in Stockholm, shape the future for people living with a rare disease!](#)

## EUROPEAN COMMISSION – JOINT RESEARCH CENTER (JRC)

The [Joint Research Centre \(JRC\)](#) is the European Commission's science and knowledge service which employs scientists to carry out research in order to provide independent scientific advice and support to EU policy.

The JRC in collaboration with DG SANTE are developing the [European RD registry infrastructure \(ERDRI\)](#) aiming to cope with the enormous fragmentation of data. It will provide EU-level solutions for data collection and data sharing. The need to access patient health information and data from different places will result in a major boost of the use in electronic data processing within the health system. As a consequence, the implementation of technological solutions allowing both the collection and exchange of patient data within registry networks will be facilitated.

Since ERDRI providing the first tools to promote the harmonization and interoperability among registries, the following workshop has been organized during this period:



- EU RD Platform ERDRI Training Workshop. 25th June 2019, Ispra - Attended by ERN IT and dissemination manager, Victoria Gutierrez Valle.

In addition, the following piece of news was launched with the release of the platform:

- [The European Platform on Rare Disease Registration has been launched!](#)

## EUROPEAN MEDICINES AGENCY (EMA)

The European Medicines Agency (EMA) is a decentralised agency of the European Union (EU). It began operating in 1995. The Agency is responsible for the scientific evaluation, supervision and safety monitoring of medicines in the EU. EMA protects public and animal health in EU Member States, as well as the countries of the European Economic Area, by ensuring that all medicines available on the EU market are safe, effective and of high quality.

EMA has established collaborations with ERNs in order to discuss the role of registries in the monitoring of cancer therapies based on genetic and molecular features and agree on recommendations about:

- Core data elements that should be collected in cancer registries to support regulatory assessment of the safety and effectiveness of new cancer treatments;
- Quality assurance measures necessary to ensure registry data are of suitable quality to support regulatory assessments and to permit registries interoperability; and
- Practical considerations for accessing/sharing data to be used for regulatory purposes.

In this context, EMA organized a multi-stakeholders workshop on the 29th November at Amsterdam with the participation of Regulators, Registry holders/representatives, Academia, Industry, Patients/HCP organisations, and Health Technology Assessment bodies.

Matteo della Porta attended in representation of ERN-EuroBloodNet as ERNs WG on registries representative for the oncological hub.

## EUROPEAN JOINT PROGRAMME (EJP) ON RARE DISEASES

The [European Joint Programme \(EJP\) on Rare Diseases](#) brings over 130 institutions from 35 countries to create a comprehensive, sustainable ecosystem allowing a virtuous circle between research, care and medical innovation. EJP has been established to further help in coordinating the research efforts of European, Associated and non-European countries in the field of rare diseases and implement the objectives of the International Rare Disease Research Consortium (IRDiRC).

ERN-EuroBloodNet has established official collaborations to participate in four of its pillars by ERN-EuroBloodNet representatives: [Achille Iolascon](#), [Marina Kleanthous](#), [Patricia Aguilar Martinez](#) and [Paola Bianchi](#).

EJP WP 14 leader, Claudio Carta, was present at the 3rd ERN-EuroBloodNet Board of Network meeting providing an overview of the Programme to the audience and highlighting the role of ERNs.

Moreover, IT and Dissemination Manager, Victoria Gutierrez Valle, attended to the International Summer School on Rare Disease Registries and FAIRification of Data (23-27 September 2019) Organised by Istituto Superiore di Sanità (ISS) and EJP.

In addition, the following pieces of news has been published for promoting the different actions provided by EJP:

- [The conference “Rare disease perspectives in Central – Eastern Europe” organized by the European Joint Programme on Rare Diseases will be held next 16th September in Poland](#)
- [EJP RD International course: Training on strategies to foster solutions of undiagnosed rare disease cases will be held 27-29 April - Register now!](#)

## EUROPEAN JOINT ACTION ON RARE CANCERS (JARC)

The [Joint Action on Rare Cancers \(JARC\)](#) is aimed to integrate and maximize efforts of the European Union (EU) Commission, EU Member States and all stakeholders to advance quality of care and research on rare cancers. Since its launch in 2016, the JARC has worked towards achieving six overarching goals, all aiming to improve rare cancer care, research and clinical outcomes across Europe.

The formal activation of the European Reference Networks (ERNs) is a cornerstone in the EU cooperation on rare cancers. In this sense, JARC has work closely with the ERNs devoted to rare cancers: [EuroBloodNet](#) (adult hematological), [ERN-EURACAN](#) (adult solid) and [ERN-PAEDCAN](#) (paediatric), namely trying to optimize the process of their development in the areas of quality of care, epidemiology, research and innovation, education and state-of-the-art definition on prevention, diagnosis and treatment of rare cancers.

After three years of work with 34 Associated Partners and 18 Member States, JARC has ended with a final meeting held 11th September 2019 at the European Parliament, where the final JARC recommendations (Rare Cancer Agenda 2030) was presented and an assessment of the state of the art and future with ERNs was analysed. EuroBloodNet was represented by

Mariangela Pellegrini who participated in the roundtable "What we would need for ERNs on rare cancers to fly". M Pellegrini was also present on the 10<sup>th</sup> September in the round table 2 "Implementation of ERNs" where EuroBloodNet was presented.

At JARC closure particular emphasis was put on the future of the ERNs addressing rare cancers and on the most efficient strategies to implement the JARC recommendations, among those the need for concrete policy actions to address the lack of systematic inclusion of rare cancers in national cancer plans. A dedicated piece of news was devoted to JARC closure event:

- [The Joint Action on Rare Cancers presents the Rare Cancer Agenda 2030 at the European Parliament](#)

## PATIENT'S ASSOCIATIONS

Patients are one of the main motor of the ERN-EuroBloodNet. The network seeks direct contact with those organizations supporting patients living with RHDs and their families. The cooperation with these entities includes listing a growing number of Associations in the ERN-EuroBloodNet website [patient's advocacy section](#).

During this period two new epags have been presented to ERN-EuroBloodNet stakeholders through the following pieces of news including a brief bio of the new representatives and their expectations on their role on the network:

- [New ePAG for rare bleeding disorders!](#)
- [New ePAG for Hemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis subnetwork!](#)

## 3.2 PROMOTION OF RELATIONS WITH NATIONAL SCIENTIFIC SOCIETIES

Contacts have already been established with National Scientific Societies identified for the dissemination of specific actions implemented by the network, ie. ERN-EuroBloodNet Thursdays webinars.

## 5. NEXT STEPS

During the third year of ERN-EuroBloodNet implementation, activities have been successfully addressed aiming to increase the outreach of the ERN-EuroBloodNet outcomes. For the prioritization of activities to be implemented during next period, feedback from ERN-EuroBloodNet SSB and members has been analysed in order to identify the more weaknesses and urgent actions to be undertaken in the dissemination field. Accordingly, some of the needs identified and dedicated actions that will be undertaken in the coming period are:

### IMPROVEMENT ON THE DISSEMINATION AT NATIONAL LEVEL

A list of contact points for the National Scientific Societies of Hematology has been created identifying the key actors in each of the organizations. All the newsletters and major pieces of news distributed among ERN-EuroBloodNet members and newsletter subscribers will be in addition sent to them in order to allow their re-distribution among their community of stakeholders.

Through this methodology the key activities and outcomes launched by the network will be much targeted distributed among the different societies at the national and European level increasing significantly the impact of the dissemination actions.

### EXPANSION OF ERN-EUROBLOODNET WEBSITE SECTIONS

ERN-EuroBloodNet website is defined by its dynamism not only in its content, but also in the evolution of its structure in the flexible way that a complex network as ERN-EuroBloodNet requires for covering its needs.

In this context, next steps foreseen are:

1. Repertory of existing patient associations across EU and Patient Associations profiles: In addition to the 11 pan-European umbrella organizations already identified and listed at the Patients' advocacy section, associations will be able to create their profiles through an easy-to-fill form, in a similar way to members' profiles. It has been agreed that the inventory should gather the following information from the patients' associations: Organization name, Country of the organization, Short description of the organization, Diseases covered by the organization, Organization contact email address, Website link of the organization, Memberships in different patient umbrella organizations.
2. Educational Material section: a dedicated section will be created including different educational material with the objective to get EU citizens, not only RD patients, aware of RHDs dimensions, values and burdens. For example it is foreseen to upload different webinars from the EHA Advocacy Sessions covering different topics: clinical trials and research, access to care and cure, patient awareness and empowerment, patients' rights.
3. Implementation of directories created under the frame of specific Transversal field of actions, eg. existing registries on RHD...
4. Establishment of electronic links with third parties: specific section dedicated to visualize the collaborative efforts and the constant relation with other projects and initiatives.

### ERN-EUROBLOODNET PLAN FOR PUBLICATIONS

It is undeniable the impact that the peer-review publications have on the health community. For this reason, it is essential to ensure the maximum level of resonance of all the actions and results obtained through the network by assuring the highest numbers of publications as possible.

In line with the ERNs monitoring indicators, ERN-EuroBloodNet is working on the definition of the strategy to improve the first results obtained through the monitoring exercises conducted, including a plan for publications.



[https://ec.europa.eu/health/ern\\_en](https://ec.europa.eu/health/ern_en)



[www.eurobloodnet.eu](http://www.eurobloodnet.eu)

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