



DELIVERABLE 2.1 ERN-EUROBLOODNET DISSEMINATION PLAN

European Reference Network on Rare Hematological Diseases

ERN-EuroBloodNet

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

Share. Care. Cure.



DOCUMENT INFORMATION

DELIVERABLE 2.1 ERN-EUROBLOODNET DISSEMINATION PLAN

Report document

ERN: **ERN-EuroBloodNet (European Reference Network on Rare Hematological Diseases)**

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Short Description

Report (EN) describing methodology to increase the outreach of ERN-EuroBloodNet actions and achievements while strengthening collaborations with RHD community and other third parties

Disclaimer:

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TABLE OF CONTENTS

1.	Introduction.....	6
1.1.	Purpose and scope.....	6
1.2.	Document structure.....	6
2.	Networking strategy.....	7
2.1.	Key Audiences and target groups.....	8
2.1.1	Healthcare professionals	9
2.1.2	Patients and their relative	9
2.1.3	National and EU policy makers and regulators	9
2.1.4	Scientific societies	9
2.1.5	Biotechnology and pharmaceutical industry.....	10
2.1.6	Non-European third parties.....	10
2.1.7	Other European Networks and Registries for RDs	10
2.2.	Stakeholders map	13
3.	Communication and Dissemination	14
3.1.	Communication plan.....	14
3.1.1	Main goals	15
3.1.2	Communication tools and materials	16
3.2.	Dissemination plan	27
3.2.1	Main goals	27
3.2.2	Dissemination tools and materials	27
4.	Conclusions.....	34

LISTS OF ABBREVIATIONS

DoA	Description of Action
C&D	Communication & Dissemination
EHA	European Hematology Association
EJP RD	European Joint Programme on Rare Diseases
EBAH	European Board for Accreditation in Hematology
ENROL	European Rare Blood Disorders Platform
ERICA	European Rare disease research Coordination and support Action
ERN	European Reference Network
ESH	European Society of Hematology
EVIDENCE	Erythrocytes Properties And Viability In Dependence Of Flow And Extra-Cellular Environment

HDs	Hematological diseases
<u>INHERENT</u>	The International Hemoglobinopathy Research Network
RDs	Rare Diseases
RHDs	Rare Hematological Diseases
WP	Work Package

LISTS OF FIGURES/TABLES

Figure 1. Key audience and target groups for ERN-EuroBloodNet.....	8
Figure 2. Overview of healthcare providers contacts from Full Members and Affiliated partners	9
Figure 3. Geographical distribution of contacts from Scientific societies	10
Figure 4. ENROL.....	11
Figure 5. Stakeholder map and segmentation priorities.....	13
Figure 6. Communication & Dissemination flows	14
Figure 7. Communication & Dissemination plan	15
Figure 8. ERN-EuroBloodNet website – Landing page.....	18
Figure 9. ERN-EuroBloodNet's Twitter profile.....	19
Figure 10. ERN-EuroBloodNet's LinkedIn company page	20
Figure 11. ERN-EuroBloodNet's Facebook profile	20
Figure 12. ERN-EuroBloodNet's YouTube channel	21
Figure 13. ERN-EuroBloodNet's monthly newsletter analysis.....	21
Figure 14. ERN-EuroBloodNet's newsletter archive	22
Figure 15. The European Commission's official logo for ERN-EuroBloodNet.....	22
Figure 16. ERN social media banners.	23
Figure 17. ERN-EuroBloodNet's official leaflet (available here in 7 languages: EN, FR, IT, ES, PT, DE, NL)	23
Figure 18. ERN-EuroBloodNet's official flyer (available here in 7 languages: EN, FR, IT, ES, PT, DE, NL)	24
Figure 19. Extract from ERN-EuroBloodNet official presentation brochure (available here)	24
Figure 20. ERN-EuroBloodNet's official poster	25
Figure 21. ERN-EuroBloodNet merchandising: branded pen, notebook, USB stick and lanyard	26
Figure 22. Screenshot from the first ERN presentation video.....	26
Figure 23. ERN Collaborative Platform – Welcome page	27
Figure 24. Dedicated archive for publications on ERN-EuroBloodNet's website	29
Figure 25. EBAH logo	30
Figure 26. Expert search	31
Figure 27. Excerpt from the list of ERN-EuroBloodNet's Full Members and Representatives	31
Figure 28. Example of a detailed member profile	32
Figure 29. Tracker of ERN-EuroBloodNet's featured events	33
Figure 30. Screenshot from one of the network's Progress meetings (Oct 2021)	33

Table 1. Main goals for communication	16
Table 2. Communication tools and target audiences	17
Table 3. Dissemination tools and target audiences.....	28
Table 4. ERN-EuroBloodNet's webinars for health professionals	30
Table 5. ERN-EuroBloodNet's webinars for patients	30
Table 6. List of key targeted events.....	32

1. INTRODUCTION

1.1. PURPOSE AND SCOPE

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

In line with [ERN-EuroBloodNet](#)'s **Specific Objective 2** (*Increase dissemination and communication of ERN-EuroBloodNet actions and outcomes on RHD within ERN and beyond*), [ERN-EuroBloodNet](#) actions aiming to ensure the communication and dissemination of the activities and results of the network are undertaken under **WP2 – Dissemination**.

This deliverable (**D2.1 – ERN-EuroBloodNet Dissemination Plan**), is presented in the framework of [ERN-EuroBloodNet](#)'s **WP2 – Dissemination**, specifically within task **T2.1– Dissemination strategy**. This document has been developed by [ERN-EuroBloodNet](#)'s [Scientific Director](#) and [Dissemination Manager](#). It describes objectives, target groups, means and methodology to increase the outreach of [ERN-EuroBloodNet](#)'s actions and achievements, while strengthening collaborations with the rare hematological disease (RHD) community and other third parties.

Thus, the main goal is to fast-track and amplify knowledge transfer between [ERN-EuroBloodNet](#) and its target stakeholder base, reinforcing the value streams of the network and capitalising on the results obtained, through the following actions:

- Operating and expanding a collaboration framework that will enable identifying and building synergies with a range of target groups and communities in the RHD space.
- Designing and implementing dissemination and communication strategies to efficiently raise awareness about the outcomes of the network, promoting activities and results among a critical mass.
- Assessing the footprint of [ERN-EuroBloodNet](#) through performance indicators, while ensuring the long-term sustainability of the network.

D2.1 represents [ERN-EuroBloodNet](#)'s overview of the Communication and Dissemination strategies and should be regarded as a living document, subject to update as the network itself grows and evolves. Consequently, a report updating this initial Communication and Dissemination plan, and summarizing the main activities and results achieved will be produced at the end of the action (**D2.2 – ERN-EuroBloodNet Dissemination report**).

1.2. DOCUMENT STRUCTURE

The present document has been structured in the following way:

- **Section 1** is the **Introduction**, where the purpose and scope of the present document are outlined.
- **Section 2** is concerned with [ERN-EuroBloodNet](#)'s **Networking strategy**, where the ecosystem of organisations within and outside the network are presented.
- **Section 3** explains the **Communication and Dissemination** strategy, where goals, tools and appropriate measures are described.
- **Section 4** outlines the **Conclusions** of this deliverable, where final remarks about these strategies are presented.

2. NETWORKING STRATEGY

ERNs are virtual networks involving healthcare providers across Europe and Norway. They aim to facilitate discussion on complex or rare diseases and conditions that require highly specialised treatment, and concentrated knowledge and resources. Among the 24 ERNs currently operating, [ERN-EuroBloodNet](#), the ERN in **Rare Hematological Diseases** (RHD), is the one working on oncological (Lymphoid malignancies and Myeloid malignancies) and non-oncological (Red blood cell defects, Bone marrow failure and hematopoietic disorders, Hematological and other iron disorders and Bleeding-coagulation disorders) rare hematological diseases.

In order to build a real network, it is essential to create synergies with other ERNs, networks and initiatives working towards objectives complementary to those of [ERN-EuroBloodNet](#). Links for collaborations have been already established and consolidated during the previous period of implementation and will be maintained in the next period (see *Section 2.1.7*)

With this in mind, the network's main efforts for this next implementation period will focus on conducting targeted campaigns to:

- Improve and expand the [European inventory of RHD experts and facilities](#) available on the [ERN-EuroBloodNet website](#) (see *Section 3.2.2.2 – European inventory of RHD experts and facilities*).
- Actively engage with **junior health professionals**, identifying and reaching out to educational bodies within the organizations involved in [ERN-EuroBloodNet](#) to establish synergies for dissemination of our educational activities within their student communities (e.g. hematologists, internists and pediatricians).
- Update the **existing contact database**.
- **Nurture current collaboration links** with established institutions like the [European Hematology Association](#) (EHA) or the [European Joint Programme on Rare Diseases](#) (EJP RD) and **explore new connections** (e.g. with the [ESH – European School of Hematology](#)).

The basis for this strategy to be successful in the establishment of a close link with the RHD community relies on the creation curation and careful monitoring of [ERN-EuroBloodNet's internal repository of stakeholders](#). This tool facilitates both the pooling and classification of the target groups by disease group leading to more efficient communication and dissemination of ERN activities. This internal repository of stakeholders allows a close link with the RHD community, scientific societies and patient organisations leading to more effective communication and dissemination of ERN-related activities. The main target audiences for [ERN-EuroBloodNet](#) are detailed below.

2.1. KEY AUDIENCES AND TRARGET GROUPS

The bidirectional communication of the network requires permanent contacts between the board of [ERN-EuroBloodNet](#) and different target groups including all health professionals involved in adult hematology (both oncology and non-oncology) and paediatric hematology (non-oncology) as well as patients and their relatives, national and EU policy-makers and regulators, industry and the European RD community.

Promoting [ERN-EuroBloodNet](#) and encouraging stakeholders to engage with the initiative requires first an understanding of its target audience. A deep-dive in stakeholder profiles and their influence along the value chain is essential to craft a successful Dissemination and Communication Plan.

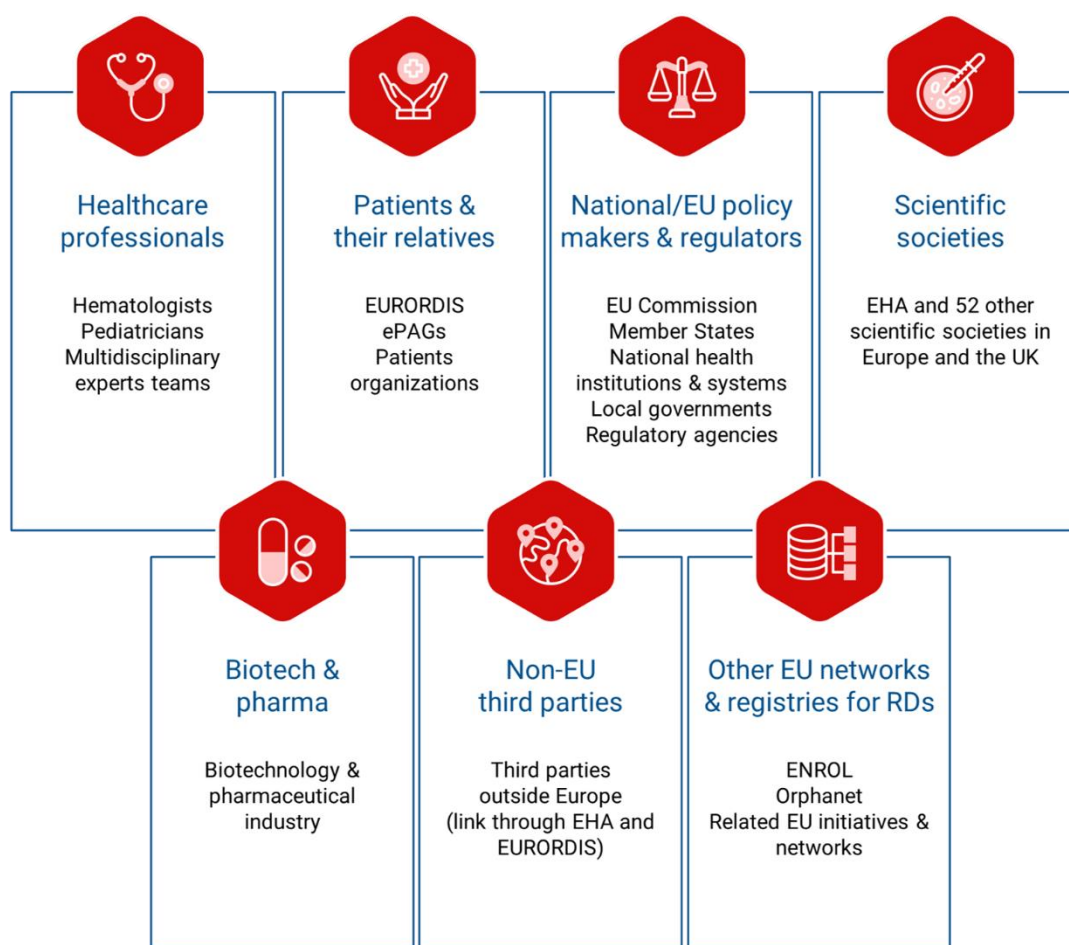


Figure 1. Key audience and target groups for ERN-EuroBloodNet

2.1.1 HEALTHCARE PROFESSIONALS

Hematologists, paediatricians, other healthcare professionals in the multidisciplinary teams as experts on bone marrow transplant, nurses, psychologists, diagnosticians and hematology researchers, who are approached mainly through [ERN-EuroBloodNet](#) channels of communication, including individual communications to [Full Members](#), [Affiliated Partners](#) and cooperation with National Scientific Societies and working groups on disease specific actions. [ERN-EuroBloodNet's repository of experts](#) includes a total of **329 contacts** from **96 members** in **18 Member States** and **7 affiliated partners** in **6 Member States**.

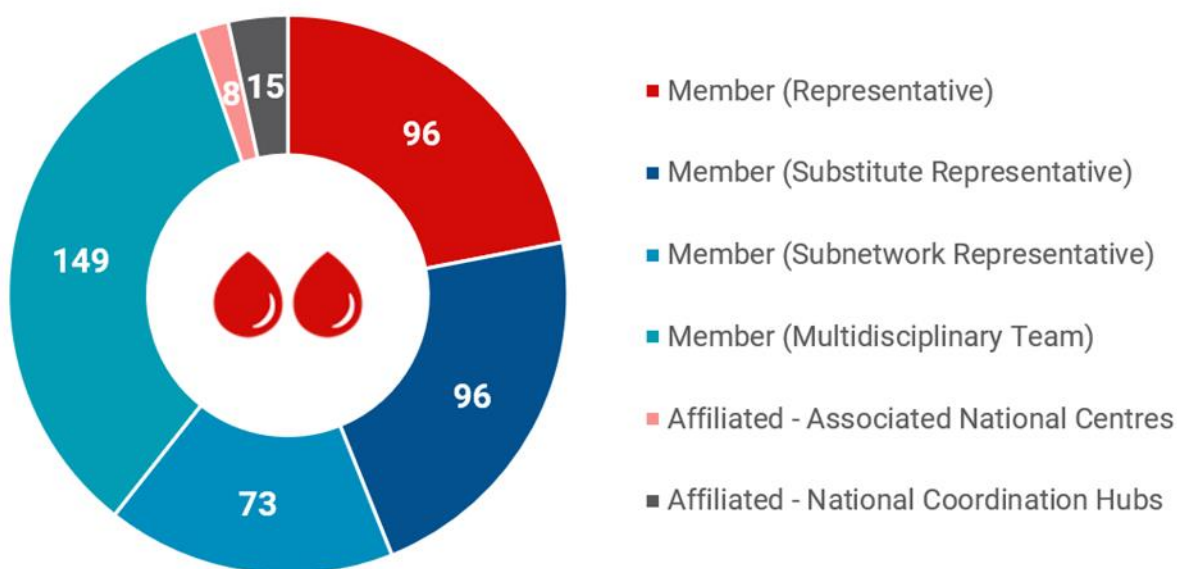


Figure 2. Overview of healthcare providers contacts from Full Members and Affiliated partners

2.1.2 PATIENTS AND THEIR RELATIVE

[EURORDIS](#) plays a key role in defining patient involvement in [ERN-EuroBloodNet](#). The elected [European Patient Advisory Groups \(ePAGs\) for RHDs](#) promoted by [EURORDIS](#) earlier in 2016 are actively involved in the different actions developed by the network (e.g. the definition of educational programs for patients, patients' organizations and patients' advocates and [ENROL](#)). Currently, in the ERN-EuroBloodNet there are [10 ePAGs](#) collaborating and formally part of the Governance. In the ERN dedicated to Rare Blood Diseases, the diseases are divided per [6 different clinical subnetworks](#) and currently one or two ePAGs are representing each subnetwork. This collaboration with [EURORDIS](#) ensures the outreach of [ERN-EuroBloodNet](#) activities and results to a broader patient community. ERN-EuroBloodNet's internal repository includes contacts of a total of **92 active patients' organizations**.

2.1.3 NATIONAL AND EU POLICY MAKERS AND REGULATORS

This category includes the [EU Commission](#), Member States, national health institutions, national health systems and public health bodies, local governments and regulatory agencies, among many others. For RDs specifically, [ERN-EuroBloodNet](#) focuses on representatives from National Ministries of Health in charge of setting up national RD registries and/or shaping policies addressing RD needs at both national and European level.

2.1.4 SCIENTIFIC SOCIETIES

The close collaboration with the [European Hematology Association \(EHA\)](#) from the beginning of the network has allowed fruitful synergies on several of areas of action, [as the development of guidelines](#) ([ERN-EuroBloodNet](#) and the [EHA](#) Guidelines Committee) or [educational actions](#). Overall, [ERN-EuroBloodNet](#) is in contact with **52 National Scientific Societies** from 25 Member States (and the United Kingdom). Similarly, the [EHA](#) gathers over 5,000 members from 100+ countries, three quarters of which are in Europe.

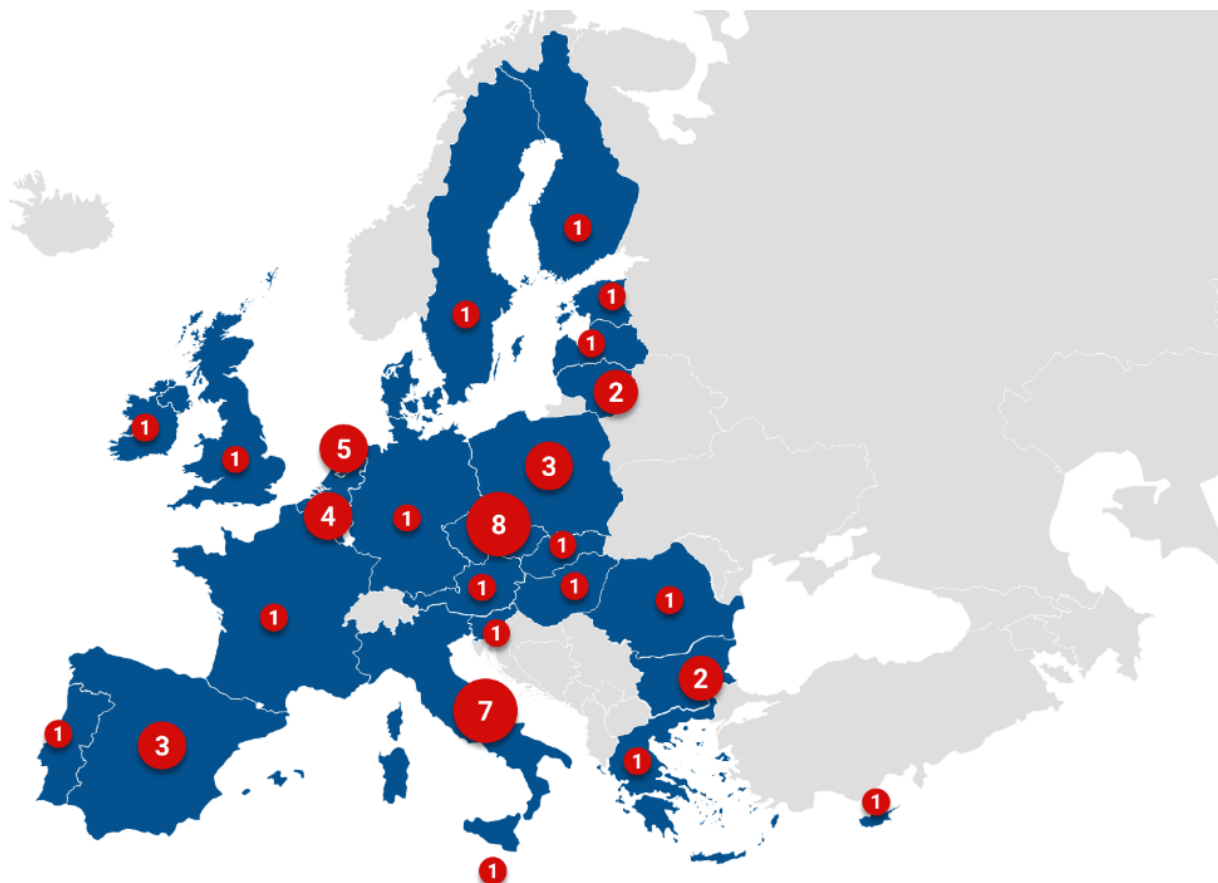


Figure 3. Geographical distribution of contacts from Scientific societies

2.1.5 BIOTECHNOLOGY AND PHARMACEUTICAL INDUSTRY

Relationships with the pharmaceutical industry to promote clinical trials and collaborative research networks will be explored through [ERN-EuroBloodNet](#).

2.1.6 NON-EUROPEAN THIRD PARTIES

Liaisons with third parties outside Europe also add value to the network by enhancing their active involvement in [ERN-EuroBloodNet](#)'s multiple activities, as well as disseminating information on RHD in neighbouring countries. Both the [EHA](#) and [EURORDIS](#) have links outside of Europe 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 ensures the long-term sustainability of our network.

2.1.7 OTHER EUROPEAN NETWORKS AND REGISTRIES FOR RDS

The Directive 2011/24/EU on cross border health establishes the creation of European Reference Networks (ERNs) based on national recognized Centres of Expertise, aiming to tackle complex or rare diseases and conditions that require highly specialised treatment and a concentration of knowledge and resources. To this end, [ERN-EuroBloodNet](#) seeks to guarantee that European citizens affected by a RHD benefit from the same level of highly specialised care, thereby improving their overall quality of life, and reducing inequalities across Europe on access to health care independent from the patient's country of origin or country of professional practice.

To carry on this purpose, [ERN-EuroBloodNet](#), governed by 3 hubs: [AP-HP, Hôpital St. Louis \(Paris\)](#), [Hôpital ERASME-CUB, LHUB-ULB \(Brussels\)](#) and [University Hospital Vall d'Hebron – Vall d'Hebron Research Institute \(Barcelona\)](#), is in charge of the coordination of experts and patients related to the RHDs field for the development of the established projects within the ERN.

Existing links and tight co-operation with other ERNs and organisations –such as [Orphanet](#)– will be strengthened at different levels (e.g. database and terminology for RDs, Orphanet-WHO ICD-11) through the development of [ENROL, the European Rare Blood Disorders Platform](#) and [ERICA – European Rare Disease research Coordination and support Action](#).

2.1.7.1 ENROL

The scarcity and fragmentation of data regarding patients affected by RHDs is one of the aspects addressed in the ERN, because it complicates the tracing of RHD patient pathways within the healthcare system and the sustainability of existing and new patients' registries established at both, National and European level. For this purpose, [ENROL, the European Rare Blood Disorders Platform](#), has been conceived in the core of [ERN-EuroBloodNet](#) to connect and facilitate upgrading of both new and already existing registries on RHDs.

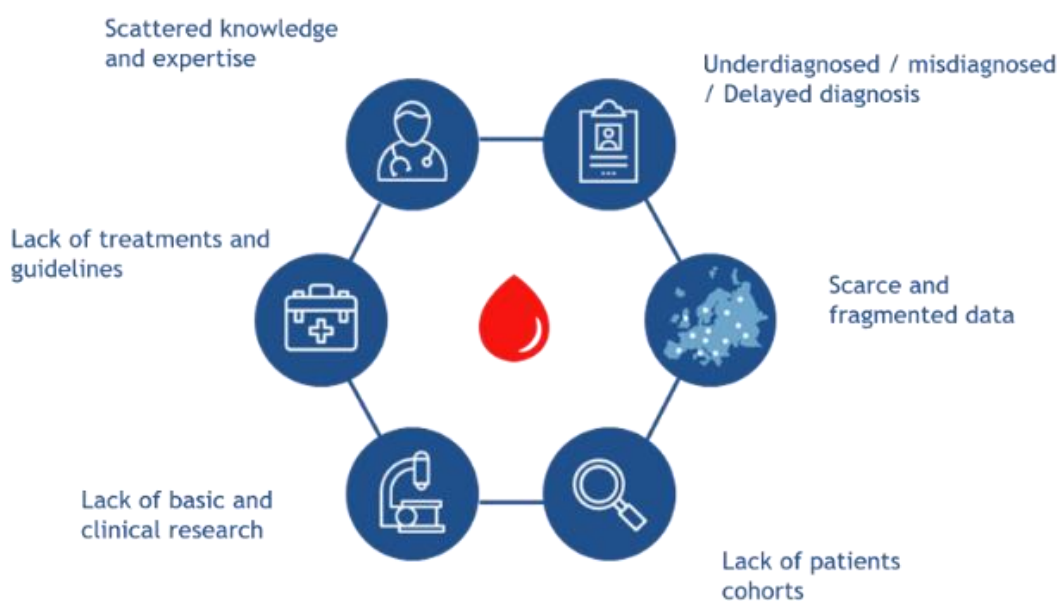


Figure 4. ENROL

2.1.7.2 ORPHANET

[Orphanet](#) was established in France by the INSERM (French National Institute for Health and Medical Research) in 1997. This initiative became an EU-wide initiative in 2000 and has gradually grown to a consortium of 40 countries, within Europe and across the globe.

[Orphanet](#) aims to gather and improve knowledge on rare diseases to improve their diagnosis, care and treatment, providing high-quality information on rare diseases and ensuring equal access to knowledge for all stakeholders. [Orphanet](#) also maintains the **Orphanet rare disease nomenclature** (ORPHAcode), essential in improving the visibility of rare diseases in health and research information systems.

2.1.7.3 RELATED EU INITIATIVES AND NETWORKS

Apart from the original call under which the network was established ([European Reference Network on Rare Hematological Disorders \(ERN-EuroBloodNet\)](#) – CHAFA HP-ERN-2016, GA 739541), ERN-EuroBloodNet is linked to and currently active in several other initiatives at European level:

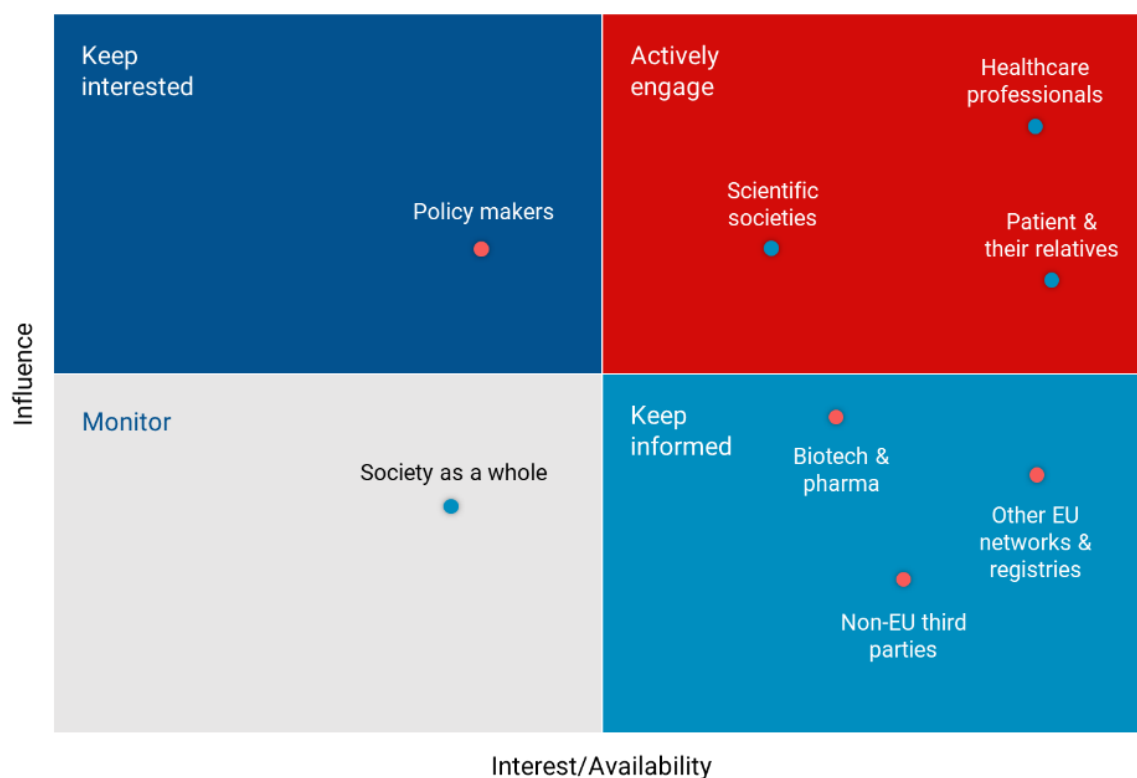
- **Connecting EuroBloodNet I-II-III** (INEA/CEF/ICT/ A2017/1526134, Action No: 2017-FR-IA-0095, INEA/CEF/ICT/A2018/1816560, Action No: 2018-EU-IA-0191, INEA/CEF/ICT/ A2020/2396236, Action No: 2020-EU-IA-0226): [ERN-EuroBloodNet](#) acts as coordinator's representative for this CEF grant to develop a stepwise approach for the efficient use of [Clinical Patient Management System \(CPMS\)](#) in the context of the [ERN-EuroBloodNet](#) and support ERN-EuroBloodNet users in the functioning of [the CPMS](#), the implementation of the [ERN-EuroBloodNet](#) e-learning platform and the development of the educational programs for healthcare professionals.

- [ERICA – European Rare disease research Coordination and support Action](#) (*H2020-SC1-BHC-2018-2020, GA 964908*): All 24 ERNs participate in [ERICA](#). [ERN-EuroBloodNet](#) co-coordinates [WP3 – Patient Centred Research](#), in close collaboration with [Orphanet](#), to facilitate the EU-wide implementation of standardized Patient-Centred Outcome Measures (PCOMs) and Patient Reported Outcome Measures (PROMs) for rare diseases while ensuring the involvement of the patient community in their development and validation process.
- [ENROL – European Rare Blood Disorders Platform](#) (*CHAFEA HP-PJ-2019, GA 947670*): The project has been conceived in the core of [ERN-EuroBloodNet](#) as an umbrella for both new and already existing registries on RHDs (see Section 2.1.7.1 for more information).
- [EVIDENCE – Erythrocytes Properties And Viability In Dependence Of Flow And Extra-Cellular Environment](#) (*H2020-MSCA-ITN-2019 (Marie Skłodowska-Curie Innovative Training Networks)*): Focused on the improvement in the access to specialized and transversal knowledge while facilitating research and the understanding of the mechanisms underlining red cell pathologies, thus increasing the generation of new knowledge, objective totally in line with [ERN-EuroBloodNet](#) key specific aim on fostering European cooperation in highly specialized procedures for diagnosis, innovative treatments and research. From the 12 partners involved, [2 are ERN-EuroBloodNet Members](#).
- [GenoMed4All – Genomics and Personalized Medicine for all through Artificial Intelligence in Haematological Diseases](#) (*H2020-DT-TDS-04-2020, GA 101017549*): [10 clinical sites from ERN-EuroBloodNet are partners in the GenoMed4All project](#), focusing on developing Artificial Intelligence algorithms for hematological diseases (Myelodysplastic syndromes, Multiple myeloma and Sickle cell disease).
- [INHERENT – The International Hemoglobinopathy Research Network](#): The international network is focused on the study of genetic modifiers for hemoglobinopathies through a large-scale multi-ethnic (30,000 hemoglobinopathy patients) genome-wide association study (GWAS). Nowadays the project involves together nine existing international or regional networks, namely [ITHANET](#), [RADeep](#), [ARISE](#), SPARCO, SADaCC, [REDAC](#), [the HVP Global Globin Network](#), the International Health Repository, and the [ClinGen Hemoglobinopathy VCEP](#).

2.2. STAKEHOLDERS MAP

The figure below depicts [ERN-EuroBloodNet](#)'s stakeholders map. The graph is structured in quadrants for influence and interest/availability:

- Y-axis shows the mutual **Influence** potential between the network and a specific target group.
- X-axis depicts the mutual **Interest or Availability** potential between the network and a specific target group.



<p>Keep interested</p> <p>High Influence Low Interest</p> <ul style="list-style-type: none"> Those with significant decision-making authority. They lack the availability or interest to be actively engaged. It is usually difficult to have consistent touch points. 	<p>Actively engage</p> <p>High Influence High Interest</p> <ul style="list-style-type: none"> Major actors with significant decision-making authority. They are typically easy to identify and actively engage with. It's important to set up consistent touch points. They can kill, sustain or expand the network.
<p>Monitor</p> <p>Low Influence Low Interest</p> <ul style="list-style-type: none"> They are not (and do not expect to be) significantly involved in the network. They may not even be aware of our network. We should know who they are. It is advised to monitor them and be aware if they move into other quadrants. 	<p>Keep informed</p> <p>Low Influence High Interest</p> <ul style="list-style-type: none"> They may be impacted by the network but have little influence. They may demand more resources than they can provide. It is necessary to find efficient ways to communicate and keep them informed (email updates, presentations, publicity campaigns).

Figure 5. Stakeholder map and segmentation priorities

3. COMMUNICATION AND DISSEMINATION

Communication and dissemination are at the core of any EU-funded initiative and [ERN-EuroBloodNet](#) is no exception. A well planned, engaging and agile communication and dissemination plan is one that considers the impact of external factors and challenges (such as the recent COVID-19 crisis) in its execution and effectiveness, and while also unlocking the potential to maximize the network's visibility and reach.

Although communication and dissemination are two interlinked activities, in this document we choose to address them separately, though always in close dependence on one another. It is obvious that similarities and convergences exist and will be examined throughout the whole lifespan of the network.

[ERN-EuroBloodNet](#)'s dynamic communication and dissemination channels (see Section 3.1.2) have been well established during the previous period of network implementation and are in constant evolution based on feedback and network's needs.

The present document aims to set the basis for the overall outreach strategy to promote and expand the awareness of [ERN-EuroBloodNet](#) goals and achievements to the different target groups identified while strengthening collaborations and relations with RHD community and other third parties, including and further expanding the following actions:

- **Maximize the impact of the actions and results obtained within the network:** updating and creating new [ERN-EuroBloodNet](#) communication and dissemination material, maintaining and stimulating [ERN-EuroBloodNet](#) media channels as powerful tools for dissemination and through continuous review, update and expansion of the [ERN-EuroBloodNet website](#).
- **Engage all stakeholders directly in the different actions carried on the ERN:** promoting dissemination of the network at International/European/National congresses and fostering collaborations with third parties and key stakeholders.
- **Inspire for the identification and development of new actions to cover gaps on the RH field,** highlight the importance of the integration of the RHD on the healthcare system.

Communication and dissemination activities are led by [ERN-EuroBloodNet Dissemination Manager](#), a dedicated member of the team in charge of directing and launching outreach activities and campaigns for the network. EU funding acknowledgements are included in all communication and dissemination materials, as well as in dissemination activities carried out in the framework of the ERN (e.g. website footer, newsletter, [YouTube channel](#), leaflets, presentations and reports).

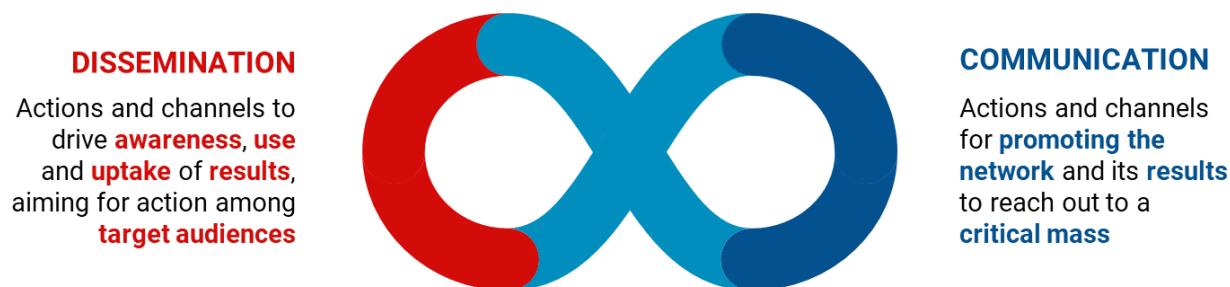


Figure 6. Communication & Dissemination flows

3.1. COMMUNICATION PLAN

To account for the versatility and agility of a coherent communication plan, [ERN-EuroBloodNet](#) adopts a funnelled approach to ensure a targeted but wide communication towards all possible target groups and stakeholders. This approach primarily focuses on generating awareness by conveying key aspects and benefits of the network to all target audiences and end users.

Easy to interpret, understand and recognize visual material will be designed and communicated allowing [ERN-EuroBloodNet](#) concepts and benefits to become instantly identifiable to a wider audience while growing and cultivating further interest towards the network and its key outcomes. Additional custom content will be produced and communicated towards specialised target groups to create and maintain an active stakeholders' ecosystem. Similarly, relevant information will be extracted from network deliverables; interviews with partners, pilot case studies; industry reports; and will be relayed through [ERN-EuroBloodNet](#)'s communication channels to further support active user engagement.

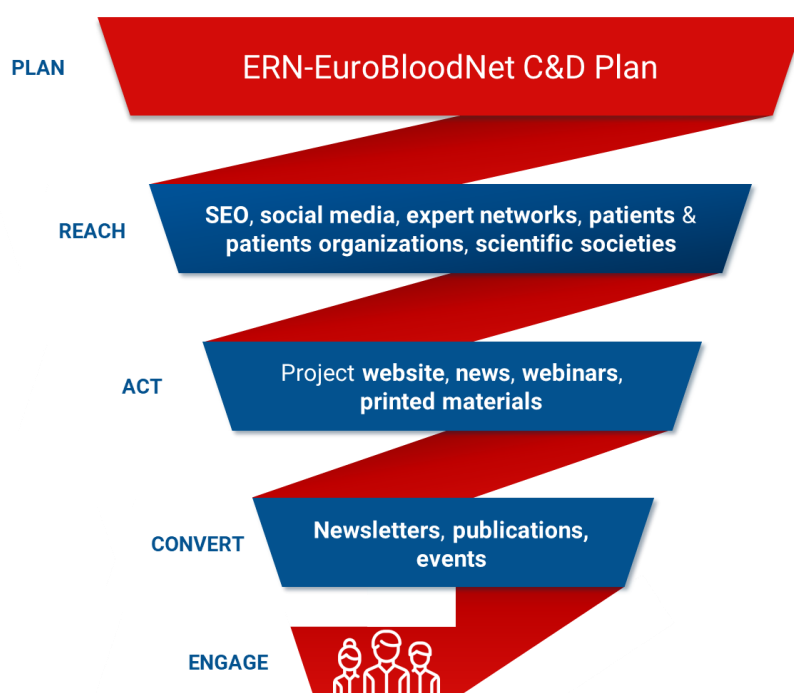


Figure 7. Communication & Dissemination plan

3.1.1 MAIN GOALS

The Communication plan is driven by some key objectives that are crucial to its deployment. Although communication objectives may be treated as a single block, some relate to specific target groups only and thus, will be approached with specific tools and activities throughout the lifespan of the network.

[ERN-EuroBloodNet](#)'s **overall objectives for communication** are:

- Increase general awareness and interest about the network to build a solid community base/ecosystem for future dissemination of results.
- Communicate technical, scientific results and benefits to [Full Members](#), [Affiliated Partners](#), specialised target groups and stakeholders.
- Deliver top-level messages about the network to non-specialized target groups and audiences.
- Raise awareness within the general public of the added value of [ERN-EuroBloodNet](#) to reach the widest possible community.

	Boost awareness & interest	Communicate scientific results	Deliver top-level messages about the network	Raise awareness in non-specialised audience
Healthcare professionals	✓	✓	✓	
Patients & their relatives	✓	✓	✓	
National & EU policy markers & regulators	✓	✓	✓	✓
Other EU networks for RDs		✓	✓	
Biotech & pharma	✓	✓	✓	
Scientific societies	✓	✓	✓	
Non-EU third parties	✓	✓	✓	

Table 1. Main goals for communication

3.1.2 COMMUNICATION TOOLS AND MATERIALS

A series of communication tools will be made available to allow the network to reach the right audiences in a friendly and coherent way. This toolkit will be tailored to specific communication needs for all phases of [ERN-EuroBloodNet](#)'s Communication plan.

[ERN-EuroBloodNet](#)'s communication and dissemination channels are continuously monitored and adapted based on user feedback and [ERN-EuroBloodNet](#)'s own needs, which evolve in line with the progression of the network itself. All channels have been well established since 2019, during the previous period of the network implementation. In this section, all tools and materials available in [ERN-EuroBloodNet](#) will be presented, together with the future roadmap to improve the efficiency of the dissemination and communication strategy according to the network's acquired experience.

	Website	Social media	Slide decks	Newsletters	Promo materials
Healthcare professionals	✓	✓	✓	✓	✓
Patients & their relatives	✓	✓	✓	✓	✓
National & EU policy makers & regulators	✓	✓	✓		✓
Scientific societies	✓	✓	✓	✓	✓
Biotech & pharma	✓	✓	✓	✓	✓
Non-EU third parties	✓	✓	✓		✓
Other EU networks for RDs	✓	✓	✓	✓	✓

Table 2. Communication tools and target audiences

3.1.2.1 ONLINE CHANNELS

Website	https://eurobloodnet.eu/
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[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 online platform that provides not only the door of access to [ERN-EuroBloodNet](#) dynamic and public [European inventory of RHD experts and facilities](#) but also to the main tools developed and implemented during the running time of the network. Since 2019, the [ERN-EuroBloodNet website](#) has received **over 170K page visits**, with a **monthly average of 5K+ visits**.

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

- As the **main tool for communication and dissemination** of [ERN-EuroBloodNet](#)'s goals and achievements to boost public awareness of the network.
- As the **infrastructure** (web portal and database) for accessing both [European inventory of RHD experts and facilities](#) such as educational material for Health Professionals and Patients.

As of now, [the website](#) includes the following high-level sections:

- General information about the network and ERNs ([objectives](#), [governance](#), [subnetworks](#), [transversal fields of action](#)).
- Membership details ([criteria to become a Full Member](#), list of [Full Members](#), [Representatives and Substitutes](#), [Affiliated](#) and [Supporting](#) partners and [European inventory of RHD experts and facilities](#)).
- A [repository of guidelines and best practices](#).
- A repository of education materials for [Healthcare professionals](#) and [Patients](#).
- Direct links to key resources, like [CPMS](#) and [ENROL](#).
- Information on [patient advocacy groups](#) and [organisations](#).

- A dedicated section on the [Collaborative Platform on Red Blood Cell and COVID-19 patients](#).
- Features for [ERN-EuroBloodNet](#)'s current research projects.
- [News archive](#).

Building on this, new sections and specific target-actions engines will be implemented in this new implementation period to further improve the usability and reach of the website:

- **360 website evaluation:** a survey will be shared among [ERN-EuroBloodNet](#)'s community of health professionals and patients and their relatives for a consultation on their website use and to collect valuable feedback on potential simplifications and updates.
- Dedicated **features for upcoming webinars and educational programs** (see Section 3.2.2.2 - Webinars) to drive additional traffic to the website for registration.
- Continuing the creation of new **experts profiles**, as a consequence of expanding the [European inventory of RHD experts and facilities](#) (see Section 3.2.2.2 – European inventory of RHD experts and facilities) available on the website.
- Complete the **Disease cards** (see Section 3.2.2.1 – Disease Cards).

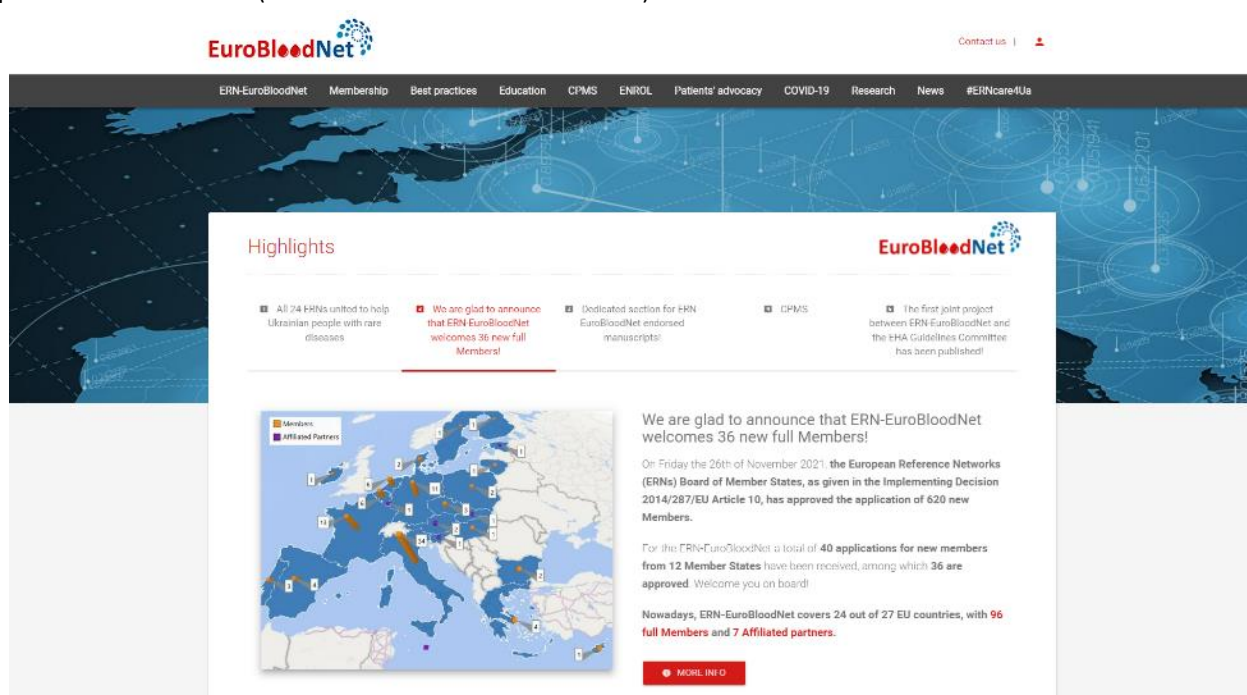


Figure 8. ERN-EuroBloodNet website – Landing page

SOCIAL MEDIA

Social media is a fast, low-cost medium to reach interest groups and communities that are normally absent at events or conferences (physical or online).

Leveraging the huge impact of social networks on the daily life and with the aim of reaching a broader audience, [ERN-EuroBloodNet](#) is connected to social networks to increase the impact of the network messages and maintains an active presence in a number of social media channels. [Twitter](#), [LinkedIn](#) and [Facebook](#) have been selected as they have proven to be most effective when engaging with the community. A [dedicated YouTube channel for the network](#) has also been set up, as a way to upload and share [ERN-EuroBloodNet](#)'s educational webinar recordings, official introductory videos and/or any other multimedia content produced.

A series of actions have been already identified to improve the current baseline for [ERN-EuroBloodNet](#)'s social media strategy in this next implementation period:

- **Real-time social media feed integration:** embedding the latest [Twitter posts](#) on the landing page of [ERN-EuroBloodNet website](#), so visitors will be able to immediately check out the latest news and traffic can be rerouted directly to the network's social media channels. This strategy will impact the number of visits, as well as increase the conversion rate of visitors to followers.

- **Targeted dissemination campaigns and promotional material:** ad hoc campaigns will be designed (together with their specific graphical assets) and launched with specific calls to action, linking to [ERN-EuroBloodNet's website](#) to increase the outreach of the materials hosted there (e.g. for dissemination of [YouTube educational webinar playlists](#), promotion of [CPMS](#) use...).
- **Membership features and spotlight:** gathering profiles names within the [ERN-EuroBloodNet community](#) with the aim to connect these campaigns directly to the authors, team, institutions or patient's organizations directly involved in or responsible for the actions.

Twitter	@ERN-EuroBloodNet
---------	-----------------------------------

[ERN-EuroBloodNet's Twitter](#) account has been active since 2019 and is currently at **1,276 followers**. Active interactions in this platform include: the rest of ERNs, EU Health, specific networks (e.g. [EJP RD](#)), patients' organizations (e.g. [EURORDIS](#) or [PNH Support](#)), scientific associations (e.g. [EHA](#))..., among many others.



Figure 9. ERN-EuroBloodNet's Twitter profile

LinkedIn

[/ERN-EuroBloodNet](#)

[ERN-EuroBloodNet's LinkedIn](#) account has been active since 2020 and currently stands at **421** followers.



EuroBloodNet - European Reference Network on Rare Hematological Diseases

EuroBloodNet aims to improve healthcare and quality of life of patients with Rare Hematological Diseases

Hospitals and Health Care · Paris, Ile-de-France · 421 followers

Figure 10. ERN-EuroBloodNet's LinkedIn company page

Facebook

[/ERN-EuroBloodNet](#)

[ERN-EuroBloodNet's Facebook account](#) was created in 2020 and currently has **310** followers.

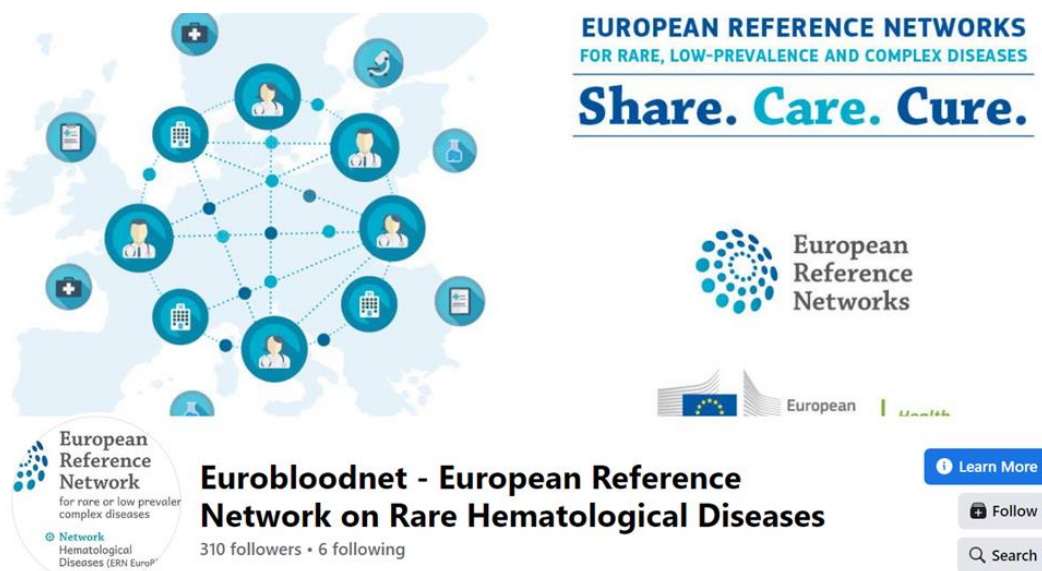


Figure 11. ERN-EuroBloodNet's Facebook profile

[ERN-EuroBloodNet's EDUcational YouTube channel](#) (with **304** subscribers as of now) has been created for the inclusion of educational videos created/endorsed by the network for the benefit of the [ERN-EuroBloodNet](#) community including both, health professionals and patients/patients organizations. [ERN-EuroBloodNet's EDU YouTube channel](#) is part of the [ERN-EuroBloodNet](#) e-Learning environment, and it includes all the webinars sessions held within the various webinars programs under the umbrella of the network. During the previous period of activity, a total of **104 videos** have been published on the platform.



Figure 12. ERN-EuroBloodNet's YouTube channel

NEWSLETTERS

As an engagement tool, online newsletters can provide a sneak-peek into the network's main activities and achievements. To set the stage and achieve wider reach and visibility, a first approach will seek to contribute directly to existing newsletters/magazines with an already established audience in [ERN-EuroBloodNet](#)'s main fields of study.

[ERN-EuroBloodNet's newsletter](#) aims to inform stakeholders about the relevant RHD news and to updated them about the development of the different networks carried on by ERN-EuroBloodNet, maximizing the impact of [ERN-EuroBloodNet](#) activities. The newsletter was launched in October 2019 and is released on monthly basis.

During this period of activity, **32 editions** have been published. The analysis of these campaigns shows an improvement on the opening and click-through rates. The charts below show the evaluation of subscriber interaction with [ERN-EuroBloodNet's monthly newsletter](#) throughout 2019 (Oct-Dec), 2020, 2021 and 2022 (Jan-June).

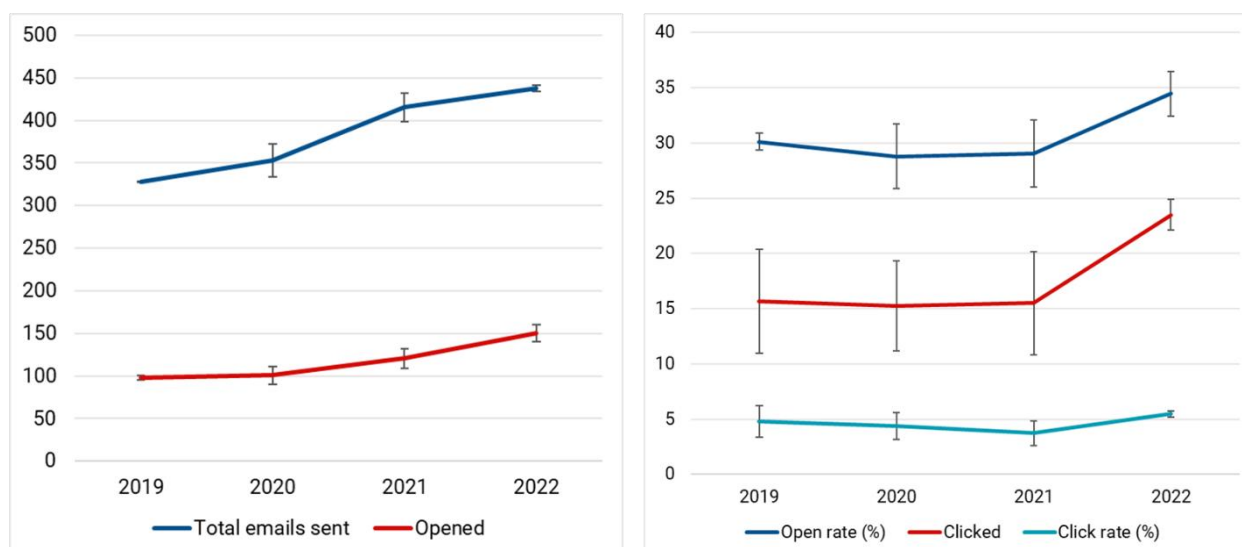


Figure 13. ERN-EuroBloodNet's monthly newsletter analysis

Although the number of subscribers has steadily increased since 2019 (the newsletter had **452 subscribers** as of February 2022), the main objective is to keep growing and boosting the outreach of [ERN-EuroBloodNet](#) results and actions. [The newsletter](#) is sent by default to all the ERN-EuroBloodNet contacts, including the current list of 52 National Scientific Societies and the EHA, which has further agreed to share the [ERN-EuroBloodNet news](#) within their own community. All editions are available at their [dedicated section in ERN-EuroBloodNet website](#).

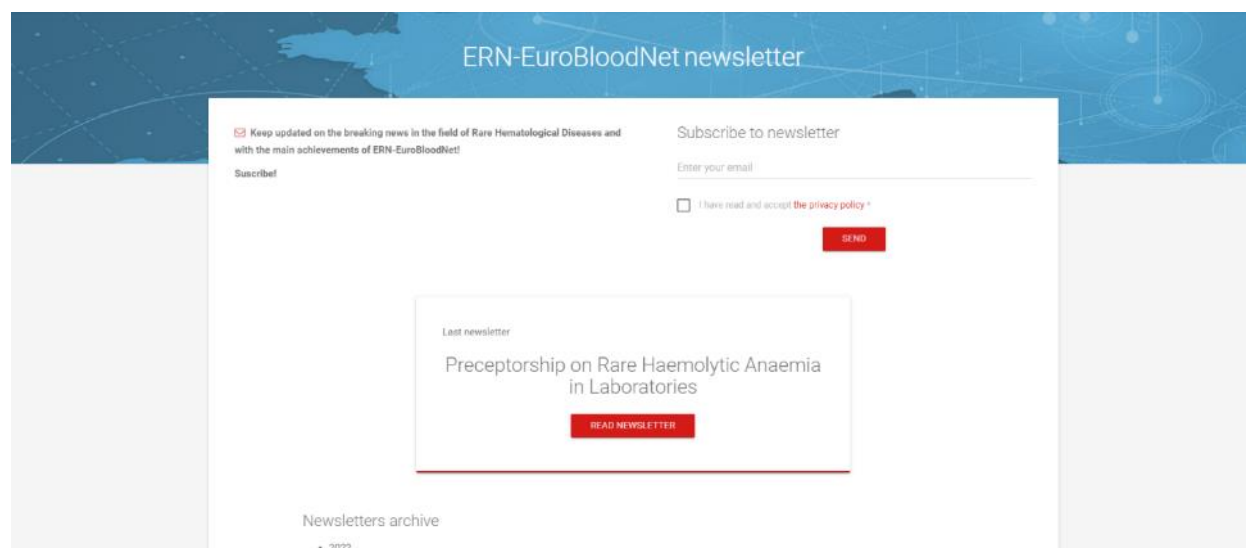


Figure 14. ERN-EuroBloodNet's newsletter archive

Main efforts going forward will focus on creating and maintaining meaningful engagement through the **design and launch of a dedicated educational newsletter**. Initially, individual newsletters and reminders were sent for each scheduled webinar. However, the progressive increase in the number of webinars and educational activities hosted by [ERN-EuroBloodNet](#) has made this practice unsustainable going forward. Consequently, there are plans to set up a new specific newsletter collating all upcoming educational activities in a given 15-day period. This periodicity will be assessed to understand how engagement changes compared to the previous strategy. Similarly, the number of registrants per webinar will be used to evaluate overall conversion rates.

3.1.2.2 PROMOTIONAL MATERIALS

Brochures, leaflets, flyers, posters... and any other resource intended for promotional use. Most of this PR material will be available in a digital format, to be printed out whenever necessary (e.g., for display in events, workshops...). Below, the main promotional materials available for [ERN-EuroBloodNet](#) are presented and described, together with future plans.

ERN OFFICIAL BRANDING AND RESOURCES

The [European Commission](#)'s official branding kit and disclaimer for ERNs is used in all promotional materials (both printed and digital).



Figure 15. The European Commission's official logo for ERN-EuroBloodNet

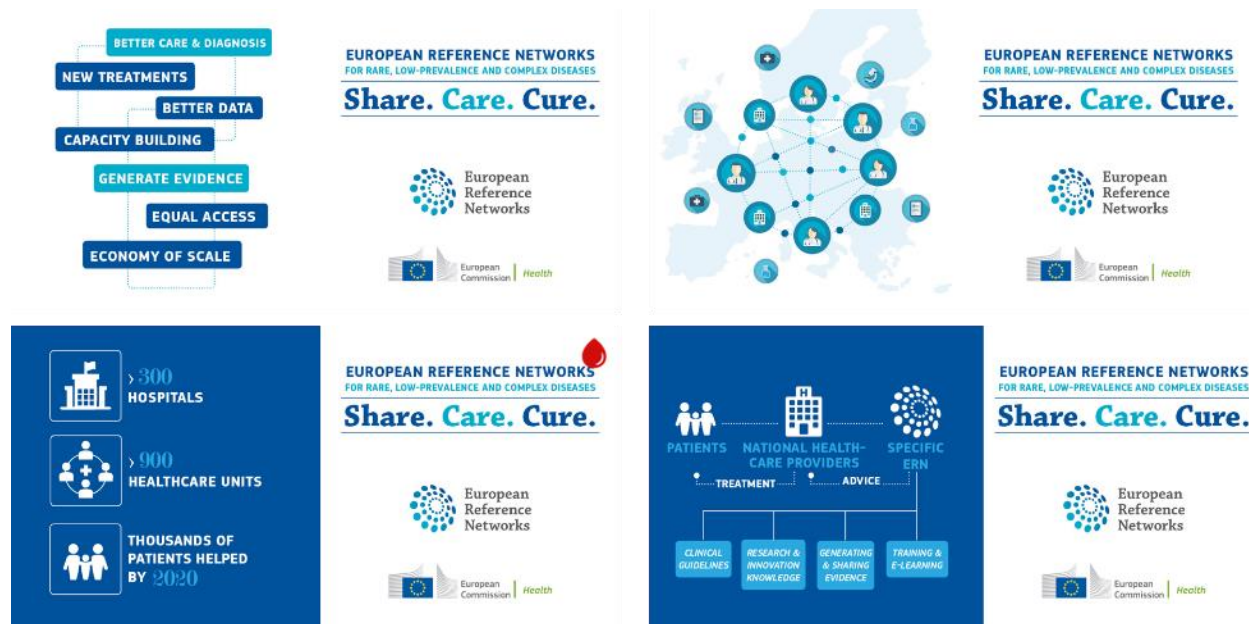


Figure 16. ERN social media banners

SLIDE DECKS, LEAFLETS, FLYERS AND POSTERS

Well-designed **slide decks** or one-pagers of the networks can be a powerful engagement tool to share the network's vision and scope with specialised audiences in a clear, attractive way. [ERN-EuroBloodNet templates](#) for the general presentation of network, together with the official **leaflet**, **flyer** and **poster** describing the network's main actions, challenges and results, will be revisited and updated (both contents and design), in order to be at the disposal of [Full Members](#), [Affiliated Partners](#) and other interested stakeholders. EU visibility (disclaimers and official acknowledge will be included in all material).



Figure 17. ERN-EuroBloodNet's official leaflet (available [here](#) in 7 languages: EN, FR, IT, ES, PT, DE, NL)

ERN-EuroBloodNet

The European Reference Network on Rare Hematological Diseases

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www.eurobloodnet.eu
Follow us on Twitter @ERNEuroBloodNet

European Reference Network
for rare or low prevalence complex diseases

European Reference Network
Haematological Diseases (ERN EuroBloodNet)

Hope for patients with rare hematological diseases

What do we offer?

- 66 highly skilled and multidisciplinary healthcare teams in 15 Member States
- Advanced specialized medical equipment and infrastructures
- Concentration of resources for the design, validation and implementation of high-quality and cost-effective services
- Patient-centred approach

Bringing together patients and health professionals to better shape clinical care.

Patients

The involvement of patients organizations in the Board of ERN EuroBloodNet has been ascertained from the outset in order to guarantee their pivotal role within the network.

EURORDIS – Rare Diseases Europe (www.eurordis.org) has established European Patient Advocacy Groups – ePAGs – for each ERN and is ensuring transversal coordination as well as providing specific training programmes.

Eight ePAGs' representatives are currently ensuring that the patient's voice is fully represented in the ERN EuroBloodNet Board and increasing the role of patients in clinical care in Europe. More ePAGs are joining as the network is developing! Stay updated at www.eurobloodnet.eu

ERN EuroBloodNet seeks to guarantee that European citizens affected by rare hematological diseases can benefit from the same level of highly specialised care, thereby improving their overall quality of life, and reducing inequalities across Europe for access to healthcare.

Professionals

ERN EuroBloodNet professionals work together to:

- Establish a European cross-border referral system for patients and samples.
- Promote evidence-based guidelines by pooling expertise within the network.
- Disseminate cutting-edge knowledge and facilitate continuing medical education.
- Provide inter-professional consultation by sharing of expertise and the safe exchange of clinical information.
- Gather the critical mass needed for the development of innovative therapies, clinical trials and cutting-edge methodologies for diagnosis.

ERN EuroBloodNet encompasses oncological (for adult patients) and non-oncological (for adult and paediatric patients) rare hematological diseases including myeloid and lymphoid malignancies, rare anemias, bone marrow failure disorders, rare bleeding-coagulation disorders and rare hereditary hemochromatosis.

Figure 18. ERN-EuroBloodNet's official flyer (available [here](#) in 7 languages: EN, FR, IT, ES, PT, DE, NL)

European Commission

European Reference Networks

Working for patients with rare, low-prevalence and complex diseases

Share.Care.Cure.

ERN on haematological diseases (EuroBloodNet)

Haematological diseases involve abnormalities of blood and bone marrow cells, lymphoid organs and coagulation factors, and almost all of them are rare. They can be subdivided into six categories: rare red blood cell defects; bone marrow failure; rare coagulation disorders; haemochromatosis and other rare genetic disorders of iron synthesis; myeloid malignancies; and lymphoid malignancies.

Diagnosis of rare haematological diseases (RHDs) requires considerable clinical expertise and access to a broad range of laboratory services and imaging technologies. These tests allow precise disease classification according to WHO criteria using inter-laboratory scoring systems and, where possible, biomarkers.

Given these requirements and the fact that some RHDs are very rare, diagnosis is frequently overlooked or delayed, especially in elderly patients. Treatment is also often difficult due to the specialised infrastructure and teams required and the difficulty accessing specific treatments such as allogeneic stem cell transplantation or coagulation factors.

Preventive programmes are in place in some countries for certain conditions, but there is an urgent need for harmonisation in the field of screening.

Preventive programmes are in place in some countries for certain conditions, but there is an urgent need for harmonisation in the field of screening.

national expertise is scarce, and to increase the number of clinical trials in the field of screening

NETWORK COORDINATOR
Professor Pierre Fenaux
Assistance Publique Hôpitaux de Paris, Hôpital Saint-Louis, France

Figure 19. Extract from ERN-EuroBloodNet official presentation brochure (available [here](#))

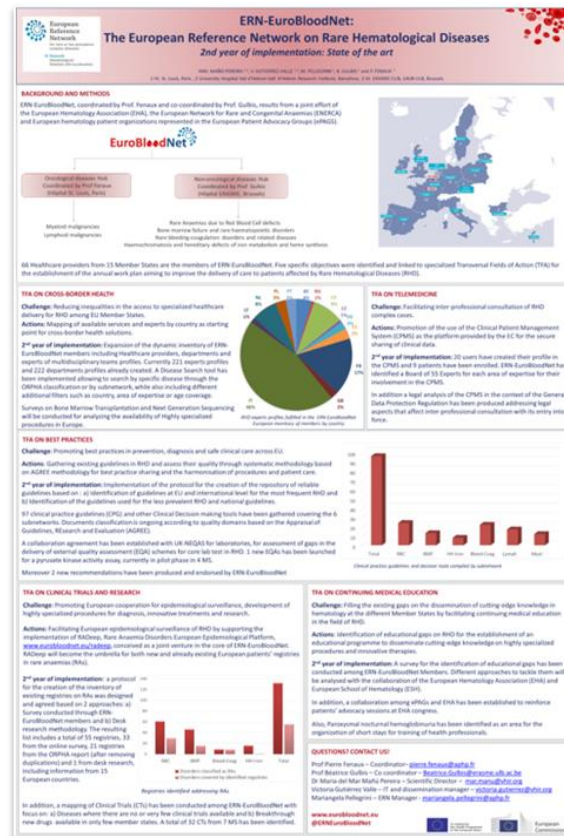


Figure 20. ERN-EuroBloodNet's official poster

C&D HANDBOOK

Aiming to promote the dissemination of the meetings and the participation of the community, an **internal handbook** with guidelines and best practices for Communication & Dissemination will be produced and made available for all [ERN-EuroBloodNet](#) for [Full members](#), [Affiliated Partners](#), and [ERN-EuroBloodNet ePAGs](#). This document will include the points that they must comply as part of the [ERN-EuroBloodNet](#), such as participation in meetings, events and conferences; commitment to include the ERN logo and disclaimers on their presentations and posters and appropriate acknowledgements in [ERN-EuroBloodNet publications](#), their reporting duties to [ERN-EuroBloodNet](#) about potential publications and presentations/posters... and much more. The handbook will also help identify and keep track of actions to be promoted through the [ERN-EuroBloodNet](#) channels.

[Full members](#), [Affiliated Partners](#), and [ERN-EuroBloodNet ePAGs](#) and other RHDs stakeholders are always welcomed to contact the [ERN-EuroBloodNet Coordination team](#) in case specific information or slides on the specific actions are required to be showcased in their talks.

MERCHANDISING

[ERN-EuroBloodNet](#) will also keep exploring other innovative alternatives such as branded merchandise (e.g. notebooks, pens, headsets, computer bags, lanyards...), showcasing both the ERN official branding and [ERN-EuroBloodNet's](#) logo.

This strategy has proved to be quite effective in reaching a broader audience, while also encouraging a more sustainable approach when considering long-lasting items. All materials will be at the disposal of the [ERN-EuroBloodNet Coordination Team](#) for their distribution to RHDs stakeholders.

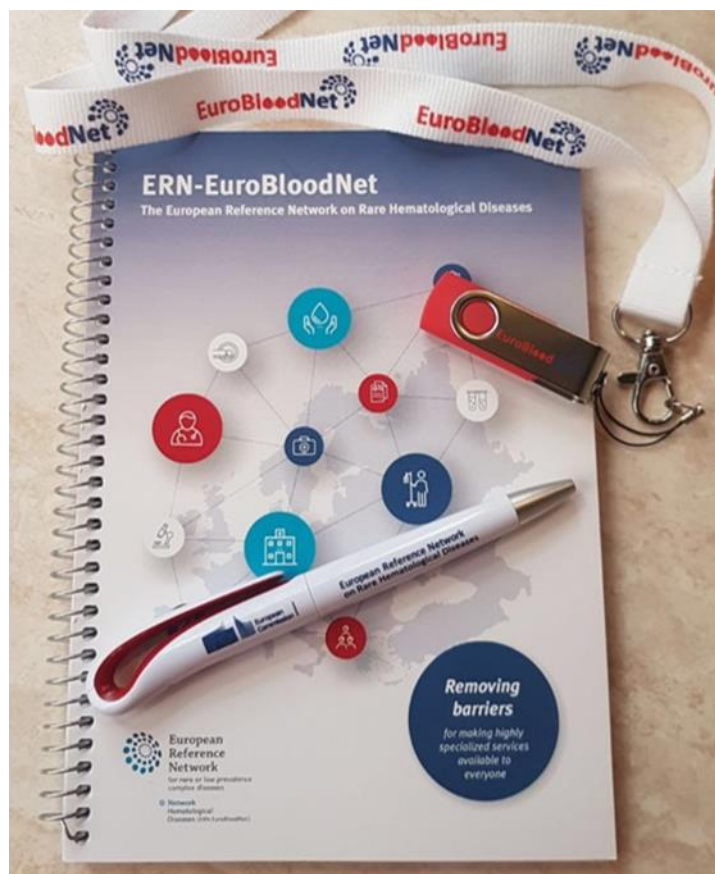


Figure 21. ERN-EuroBloodNet merchandising: branded pen, notebook, USB stick and lanyard

MULTIMEDIA

Multimedia material is a self-explanatory and appealing way of introducing the network to a critical mass through well-known channels (e.g., [YouTube](#)). Following in the footsteps of the [first official presentation video for all 24 ERNs](#), in this period of implementation the network intends to produce a **video on ERN-EuroBloodNet objectives and key actions** addressing the general audience is envisaged, including subtitles in different languages (English, French, Spanish, Italian and German) to boost the outreach of the video across the EU and beyond.



Figure 22. Screenshot from the first ERN presentation video

3.1.2.3 INTERNAL COMMUNICATION

COLLABORATIVE PLATFORM

The [ERN Collaborative Platform](#) developed by the EC is an excellent platform for internal communication and sharing of documents among [ERN-EuroBloodNet Full Members](#) and [Affiliated Partners](#). As in previous periods, its use has been promoted by uploading of exclusive material of interest for our community.



Figure 23. ERN Collaborative Platform – Welcome page

3.2. DISSEMINATION PLAN

Dissemination is key for [ERN-EuroBloodNet](#), as it aims not only to share results with potential users and research peers, patients, the healthcare sector and policy makers, but also make these results available to the wider community. To this end, [ERN-EuroBloodNet](#) has developed a flexible dissemination plan that intends to raise awareness of network results, promoting understanding and encouraging action among key target audiences. The execution of this plan will facilitate the uptake of outcomes and best practices, as well as research insights produced throughout the network's lifetime, thus reinforcing the impacts described in the DoA.

3.2.1 MAIN GOALS

Dissemination goals have been previously described in the DoA. These goals are interlinked with those already set for communication activities and also with the overall network objectives: they are all geared towards creating an impact beyond the boundaries of the network.

3.2.2 DISSEMINATION TOOLS AND MATERIALS

As mentioned, Communication and Dissemination activities are inherently interlinked and therefore some tools are shared between both. Below is the list of specific dissemination tools envisioned for [ERN-EuroBloodNet](#).

	Network documentation	Peer-reviewed publications	Disease Cards	Webinars	Events	Experts repository
Healthcare professionals	✓	✓	✓	✓	✓	✓
Patients & their relatives	✓	✓	✓	✓		✓
National & EU policy makers & regulators	✓				✓	
Biotech & pharma	✓	✓	✓		✓	
Scientific societies	✓	✓	✓	✓	✓	
Non-EU third parties	✓	✓	✓	✓		
Other EU networks for RDs	✓			✓	✓	✓

Table 3. Dissemination tools and target audiences

3.2.2.1 PROMOTIONAL MATERIALS

NETWORK DOCUMENTATION

Documentation material in the form of public deliverables will be made available through [the CHAFAEA Health Program Database](#) and the [ERN-EuroBloodNet's website](#). Any other type of public documentation will also be accessible through the [network's official website and its current repositories](#) (e.g. ERN-EuroBloodNet's public repository for deliverables at [CHAFAEA's Health Programmes Database](#)).

PEER-REVIEWED PUBLICATIONS

[ERN-EuroBloodNet](#) intends to publish and contribute to peer-reviewed publications in top scientific journals to ensure that technical and clinical achievements and experimental findings are adequately showcased and made available to a larger research community and scientific domains to further collaboration and research. This ambition is aligned with our milestones (**MS4 –ERN-EuroBloodNet peer review publications**: 3 peer-reviewed publications on different actions of the network. Publications made in indexed scientific journals and available at PubMed).

To tackle this point, [ERN-EuroBloodNet](#) will identify topics on transversal and specific ongoing actions. The [ERN-EuroBloodNet Coordination team](#) will be involved in this action and all manuscripts produced will be Open Access.

Publications of ERN-EuroBloodNet Members and Affiliated Partners			
Publications of ERN-EuroBloodNet Members and Affiliated Partners			
Find below the list of Publications accredited by ERN-EuroBloodNet:			
Publication Date	Title	Authors: ERN-EuroBloodNet Experts and their affiliations	Member States Involved
18 th October 2018	Newborn screening for sickle cell disease in Europe: recommendations from a Pan-European Consensus Conference	Stephan Lobitz, Paul Telfer, Elena Cela, Carolina Backman Johansson, Catherine Badens, Celeste Bento, Marianne de Montalembert, Béatrice Gulbis, Baba Inusa, Marina Klenthous, Joachim Kunz, Lisa Langabeer, Corina McMahon, Raffaella Colombatti	Belgium, Cyprus, France, Germany, Italy, Portugal, Sweden, The Netherlands, Switzerland and Spain
Paola Bianchi (Foundation IRCCS Ca'Granda Ospedale Maggiore Policlinico, Milan), Elisa			

Figure 24. Dedicated archive for publications on ERN-EuroBloodNet's website

DISEASE CARDS

Additionally, the network is currently working on the development of so-called **Disease Cards** (see *Section 2.1.7.1* for more details). This section aims to become a curated repository of [ERN-EuroBloodNet](#)'s actions and materials classified by disease groups.

This tool has been developed to link the authors, teams and centres involved in each effort and ongoing action through the [profiles of the European inventory of RHD experts and facilities](#). During this new implementation period, the following modules will be integrated under the Disease Cards section:

- A relation of Reference Centres and Experts for each disease group (i.e. an [European inventory of RHD experts and facilities filtered by disease group](#)).
- A catalogue of **profiles from patients' organizations and supporting groups** currently active within the diseases targeted by [ERN-EuroBloodNet](#), including direct links to their official websites.
- A **compendium of guidelines** in the repository related to each disease group, with direct links to the original reference documents.
- An **educational corner** devoted to the two primary target audiences in [ERN-EuroBloodNet's](#) educational program: health professionals and patients and their relatives.
- A **Repository of Observational Studies, Clinical Trials and Publications** endorsed by [ERN-EuroBloodNet](#) and directly linked to the profiles of the network's experts involved.
- A dedicated section devoted to **ongoing projects** carried on by [ERN-EuroBloodNet's](#) community within each disease group (e.g. Webinars Programs dedicated to each specific disease group or [CPMS](#)).
- A comprehensive list of the diseases covered by each disease group.

3.2.2.2 ONLINE CHANNELS

WEBINARS

ERN-EuroBloodNet educational webinars for patients, families of patients and patients' organizations. The webinar's teaching objectives are defined by [ERN-EuroBloodNet coordination team](#), experts and/or patient organizations, with the overall ambition that the program successfully addresses educational gaps within a specific RD. Speakers in these webinars are either an expert in that RD or a duo of a health professional and a patient representative for each lecture. The program is geared towards health professionals, patient organizations or patients and their families and offers unrestricted open access worldwide to both the webinar live sessions and the recorded e-learning modules. Additionally, some of the network's webinar series for healthcare professionals are accredited with continuing medical education credits through the [European Board for Accreditation in Hematology](#) (EBAH).



Figure 25. EBAH logo

All webinars are uploaded to ERN-EuroBloodNet's EDU channel on YouTube. Right now, the webinar numbers are as follows:

Webinar series for Professionals	No. webinars	Credits
<u>Thursday Webinars</u>	<u>30</u>	
<u>Topic on Focus: Cutaneous Lymphoma</u>	<u>9</u>	7 CME credits
<u>Topic on Focus: Thrombotic Microangiopathies</u>	<u>15</u>	11 CME credits
<u>Topic on Focus: Bone Marrow Failure Syndromes</u>	18	18 CME credits
<u>Spotlight on Castleman's Disease</u>	4	4 CME credits

Table 4. ERN-EuroBloodNet's webinars for health professionals

Webinar series for Patients	No. webinars
<u>Patients Webinars</u>	3
<u>Topic on Focus: Cutaneous Lymphoma</u>	6
<u>Topic on Focus: Myelodysplastic Syndromes</u>	8
<u>Topic on Focus: Sickle Cell Disease</u>	11

Table 5. ERN-EuroBloodNet's webinars for patients

EUROPEAN INVENTORY OF RHD EXPERTS AND FACILITIES

The [Inventory of Experts and facilities](#) available on [ERN-EuroBloodNet's website](#) is an exhaustive online catalogue and [search engine](#) of expert references for patients and their families. During this period of implementation, the network will design and lead targeted campaigns aiming to improve the current information on experts and identify new ones for each [Full Member](#) (a total of 96 as of now) and [Affiliated partners](#) (7 overall). These newly identified experts will also be included in the list of key stakeholders to broaden the scope through the addition of other key profiles (e.g. nurses, scientists...) that are also an integral part of these multidisciplinary teams.

Figure 26. Expert search

Member n°	Country	Member name	Representative name	Substitute representative
1	FR	Assistance Publique Hôpitaux de Paris, Hôpital Saint-Louis	Régis Peltault de Létour	Pierre Feraux
2	BE	CUB-Hôpital Erasme	Béatrice Gubis	Florence Roufasse
3	DE	Jules Bordet Institute	Dominique Bron	Sebastian Wittnebel
4	BE	University Hospital Leuven	Kathelijn Peeterlinck	Chris Van Geet
5	DE	University Hospital Liège	Yves Beguin	Frédéric Baron
6	BE	University Hospitals Saint-Luc	Cedric Hermans	Catherine Lambert
7	BG	Varia Expert Center of coagulopathies and rare anemias	Valeriya Kaleva	Elina Peteva
8	BG	Expert Center on coagulopathies and Congenital Anemias	Toshko Lissitchkov	Stanislav Simeonov

Figure 27. Excerpt from the list of ERN-EuroBloodNet's Full Members and Representatives

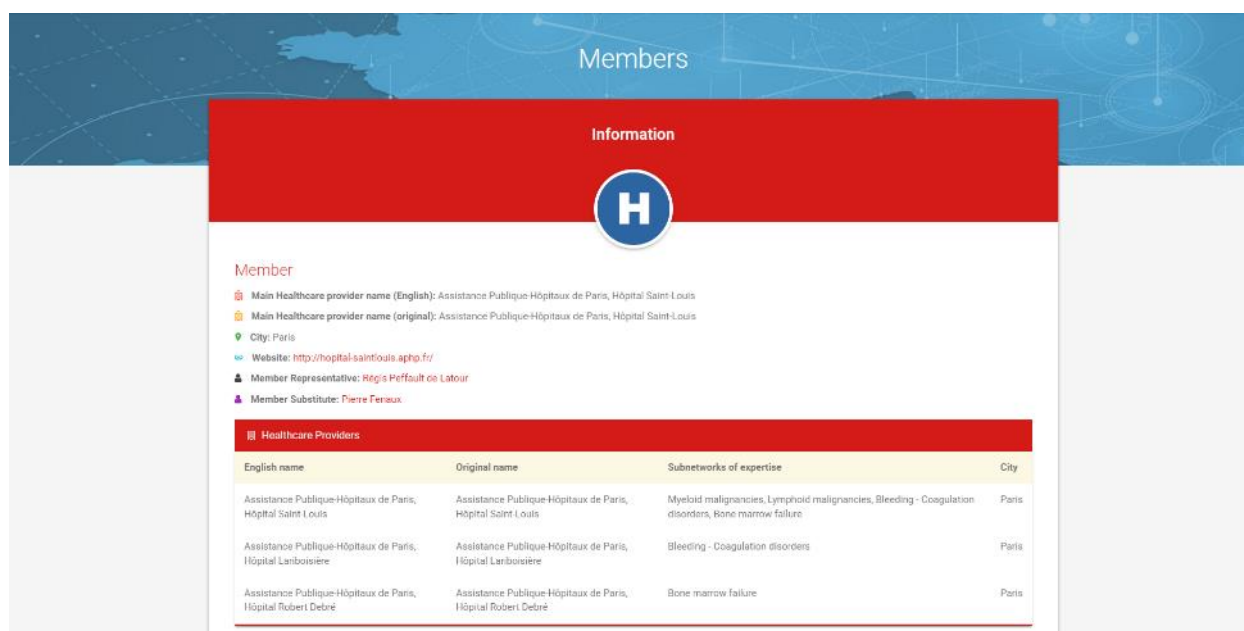


Figure 28. Example of a detailed member profile

3.2.2.3 EVENTS

[ERN-EuroBloodNet's Full Members](#) are devoted to spread the messages and services of the network in every forum that might be relevant to strengthen the network. Health professionals and patients and patients relatives as well as patients advocates are encouraged with the support of [ERN-EuroBloodNet Coordination team](#) to spread relevant actions and results of the network at International/European/National congresses, meetings and workshops.

Below is an indicative list of events that have been identified by [ERN-EuroBloodNet](#) as main targets. This list will be continuously updated with inputs from partners and depending on the maturity of the network at a given stage. It is also worth noting that right now, the majority of events are pivoting to the online scene, as a consequence of the COVID-19 pandemic.

The network will disseminate outcomes by means of presentations, talks and personal engagement. This includes participation in dedicated events, such as conferences, seminars and workshops as a strategic mechanism to actively interact and engage with multiple stakeholders at a time.

Event	Periodicity
Sickle Cell and Thalassemia Conference (ASCAT) for patients	Annual
European Red Cell Society Meeting (ERCS)	Annual
EHA Congress	Annual
ASH Meeting & Exposition	Annual
Global Sickle Cell Disease Congress	Annual
European Conference on Rare Diseases & Orphan Products (ECRD)	Annual

Table 6. List of key targeted events

To keep track of the community's participation in events, [ERN-EuroBloodNet's website](#) also includes an [archive of events](#) where the network's results have been showcased, for full traceability.

ERN-EuroBloodNet Results Presented in Events

The dissemination of activities and outcomes achieved by the ERNs is a cornerstone to ensure a wide impact among the Rare disease community, including health professionals, patients and other stakeholders. ERN EuroBloodNet actions and results have been presented acknowledging the ERN in the following events:

Date of the Event	Slot in the Agenda	Event	Emplacement of the Event	Representatives
30 th January 2019	ERN-EuroBloodNet activities	2nd Meeting of Italian EuroBloodNet HCPs	Italy	
2 nd February 2019	ERN-EuroBloodNet activities	Local annual meeting on haemoglobinopathies	Cyprus	Marina Kleantous
14 th March 2019	ERN EuroBloodNet activities	ICKSH meeting	Korea	Marta del Mar Morán Pereira
29 th March 2019	Establishment of an European Network of Sickle Cell Disease Patients Organization	Italian National Meeting at Hospital Policlinico Milano	Italy	Mariangela Pellegrini
4 th April 2019	ERN-EuroBloodNet activities	5th SSB meeting	Belgium	SSB
8 th April 2019	Improving registries and clinical trials for rare diseases	Assessment of a European Expert Network on communicable diseases and other rare pathologies in the context of Mobility and Globalisation	Spain	Marta del Mar Morán Pereira
9 th May 2019	Telemedicine on the European platform	Belgian Hematology Society - Red Blood Cell Committee	Belgium	Fabrizio Alessini

Figure 29. Tracker of ERN-EuroBloodNet's featured events

ERN-EUROBLOODNET INTERNAL MEETINGS

The [ERN-EuroBloodNet Coordination team](#) organizes two different types of meetings: the **BoN** (Board of the Network) and **Progress** meetings. During this previous period, **4 meetings** have been held overall (2 BoN and 2 Progress meetings).

From the very beginning of ERN-EuroBloodNet, the Coordination team has arranged and organized **meetings for the Board of the Network** (BoN) to create and maintain the co-operation momentum target-driven on site. As a result of the COVID-19 pandemic, the [ERN-EuroBloodNet](#) community had to adapt their coordination activities and pivot from face-to-face to online social events and regular internal meetings. The upside of this situation is that online meetings have proven to be more accessible to the community and contribute to increase the outreach of the network's ongoing actions.

An example of this are **ERN-EuroBloodNet Progress meetings** gathering the whole BoN every 6 months (spring and autumn), which had been held online to boost cooperation and provide detailed information on all the ongoing actions implemented. There is the expectation for these meetings to go back to a face-to-face setting in the short to medium term, if the current COVID-19 situation keeps evolving favourably.



Figure 30. Screenshot from one of the network's Progress meetings (Oct 2021)

4. CONCLUSIONS

Throughout this document (EU4H-2022-ERN-IBA, GA No. 101085717), the development of several actions for communication and dissemination for [ERN-EuroBloodNet](#) has been described, with the ultimate goal to target our 7 key target groups (see *Section 2.1 – Key audience and target groups*).

First, the [ERN-EuroBloodNet website](#) –the main online platform of the RHD ERN– will be expanded and updated according to improve the experience of the user and increase the outreach of the actions developed.

Secondly, ERN-EuroBloodNet's social media channels and [newsletters](#) will operate as the main tools to disseminate and promote *ad hoc* campaigns focusing on the work and results of the ERN, together with relevant information for the RH community as a whole (e.g. updated dissemination material, publications, videos... etc.).

Furthermore, communications and interaction among [ERN-EuroBloodNet](#) and its stakeholders will be managed and executed periodically through ERN-EuroBloodNet's meetings to ensure alignment and foster involvement on all actions developed, identify new potential actions to explore and establish collaborations among the ERN-EuroBloodNet community.



European
Reference
Networks

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



European
Reference
Network

for rare or low prevalence
complex diseases



Network

Hematological
Diseases (ERN EuroBloodNet)

www.eurobloodnet.eu



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