



DELIVERABLE 7.3 CPMS ACTIVITY BY ERN-EUROBLOODNET MEMBERS 3

ERN-EuroBloodNet: European Reference Network on Rare Hematological Diseases

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

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DOCUMENT INFORMATION

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Report Document

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

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Short Description

Report on CPMS activity by ERN-EuroBloodNet members: number of cases, type of consultation, time of response.

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1. INTRODUCTION

INTRODUCTION OF THE CURRENT SITUATION OF THE CPMS

European Reference Networks and the Clinical Patient Management System

The objective of the Clinical Patient Management System (CPMS) is to support European Reference Networks (ERNs) in the diagnosis and treatment of rare disease or low prevalence complex disease or conditions across national borders.

ERNs are connected through a dedicated IT platform (CPMS) through which an ERN can convene 'virtual' advisory boards of medical specialists using telemedicine tools to review a patient's condition for diagnosis or treatment. This allows health professionals, who would previously have handled rare and complex cases in isolation, to consult peers and seek a second opinion from a panel of experts. A central feature of these tools is interoperability. Thanks to technology, geographical distance does not need to be a barrier to working in dispersed teams. ERNs use the CPMS to share medical information and high-resolution images (e.g. MRI and CT scans) of rare and complex conditions. These technologies can also be used as a repository of cases, helping to build a large bank of cases for further research.

CPMS is web-based and cross-platform accessible for end-users and is backward compatible with the most common operating systems, devices (computer, tablet, smart phone). Bringing expert specialized care to all patients in Europe the diagnosis and treatment of rare or low prevalence complex diseases or conditions across national borders: The system allows for virtual consultation across national borders, ensuring that the needed expertise can travel to the patient, instead of the other way around.

After the first version of the CPMS was released on November 20th, 2017 and a pilot phase was undertaken until March 2018, EuroBloodNet together with other ERNs have started to work towards increased its implementation among members of the network and efficient usage to share the knowledge and consult rare cases crossborders. Until know to CPMS has joined 2528 active users, created 2303 panels for consultation, and successfully closed 1122 patients cases (according to the ERN Status report January 2022).

ERN-EuroBloodNet Operational Helpdesk

The EuroBloodNet's CPMS helpdesk was established as a part of the call CEF TELECOM CALL FOR PROPOSALS 2017 CEF-TC-2017-2 for the project "Connecting EuroBloodNet" (2017-FR-IA-0095, 1/10/2018-30/09/2019). To continue the work of the ERN-EuroBloodNet Operational helpdesk manager was hired in January 2020 in the co-coordinator centre of the network, CUB-Hôpital ERASME, Brussels, to support the communication and understanding between the users in HCPs and the Core services IT engineers. Besides this, the CPMS Helpdesk is in charge of registration of CPMS users and technical support for the ERN members, non-members and affiliated partners who would like to contribute to the consultations in CPMS. This is done in a multiple approach by :

- a) providing technical support after the request of the user
- b) promoting and creating practical user guides
- c) organizing trainings online/onsite trainings
- d) management and monitoring of CPMS panels
- e) support and administration of CPMS video clinical meetings
- f) identification of technical issues and collaboration with Core services IT team on providing rapid solution

Continuing the efforts of actions developed under "Connecting EuroBloodNet" and "connecting EuroBloodNet II" actions funded by the call CEF TELECOM CALLS FOR PROPOSALS 2020 CEF-TC-2020-2 for 'Connecting EuroBloodNet III' (2020-EU-IA-0226, 01/10/2021-28/02/2023) aims to a) promote the wide implementation of the CPMS while ensuring its efficient use, b) scale up the actions initiated under "Connecting EuroBloodNet" and "Connecting EuroBloodNet II" for the implementation of customized sets of data elements according to the ERN-EuroBloodNet needs.

Synergies with the ERN-EuroBloodNet Transversal Fields of Action (TFA) on Telemedicine have been established for both Connecting EuroBloodNet I, II and III in order to allow the creation of a symbiosis between both actions for joining efforts while avoiding duplication of efforts and related costs. Specially, strong collaborations have been devoted for the promotion of CPMS where dedicated efforts have been focused on increasing the awareness on the CPMS and its rationale between medical and patients' community.

2. OBJECTIVES

One of the key objectives established by ERN-EuroBloodNet is to provide inter-professional consultation by sharing of expertise and safe exchange of clinical information through the Clinical Patient Management System, as the platform supporting European Reference Networks in facilitating the decision making for the diagnosis and treatment of rare disease or low prevalence complex diseases or conditions across national borders.

Accordingly, the specific objectives for this Deliverable are:

- To analyse ERN-EuroBloodNet CPMS activity based on the performance indicators
- Continuation of the ERN-EuroBloodNet's strategy towards efficient use of CPMS among the network members and non members resulting in increased number of users, panels, geographical and disease coverage

3. METHODS

TASK 1. ANALYSIS OF ERN-EUROBLOODNET CPMS ACTIVITY BASED ON PERFORMANCE INDICATORS

The activity of ERN-EuroBloodNet CPMS is based on Performance Indicators accessible only for the CPMS coordinator.

In this section logarithms collects data in the form of reports on activity, active users, panels closed and panels created and thematic groups for all created panels.

TASK 2. ERN-EUROBLOODNET STRATEGY FOR PROMOTING THE WIDE IMPLEMENTATION OF THE CPMS

2.1 CPMS PROMOTION AND INCREASE OF AWARENESS

To ensure the efficient use and wider outreach among the rare hematological diseases health professionals, the promotion of the CPMS within and outside ERN-EuroBloodNet is crucial.

In close collaboration with the actions developed during the Connecting EuroBloodNet I and II grants, EuroBloodNet actions aims at rising the awareness on the CPMS and promoting its use among health professionals to advise complex case and exchange their expertise.

Moreover, the efficient use of the CPMS by the highly heterogenous and, in most occasions, with low agenda availability health care community, using different IT infrastructures, require instant support and creation of simplified IT guides to understand the functionality of the platform. To reach these goals several efforts has been made:

Online bulletins

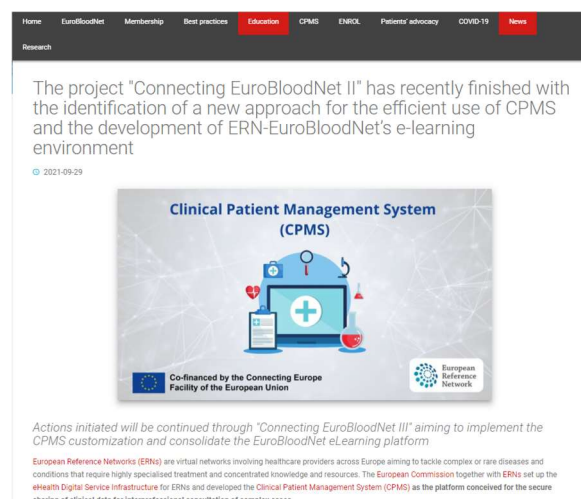
To promote the active involvement of CPMS users, dedicated emails were sent aiming:

- Encourage users to open panels
- Remind key steps on the use of platform
- Send the links to CPMS section [How to use the CPMS](#) with one page guides and videos produced by the network during the previous period of implementation

Moreover, a piece of news for disseminating the end of the project Connecting EuroBloodNet II and starting of the continuation through Connecting EuroBloodNet III was disseminated:

[The project "Connecting EuroBloodNet II" has recently finished with the identification of a new approach for the efficient use of CPMS and the development of ERN-EuroBloodNet's e-learning environment](#)

This information was also shared on [ERN-EuroBloodNet newsletter](#) and social media channels: [Facebook](#), [LinkedIn](#), [Twitter](#)

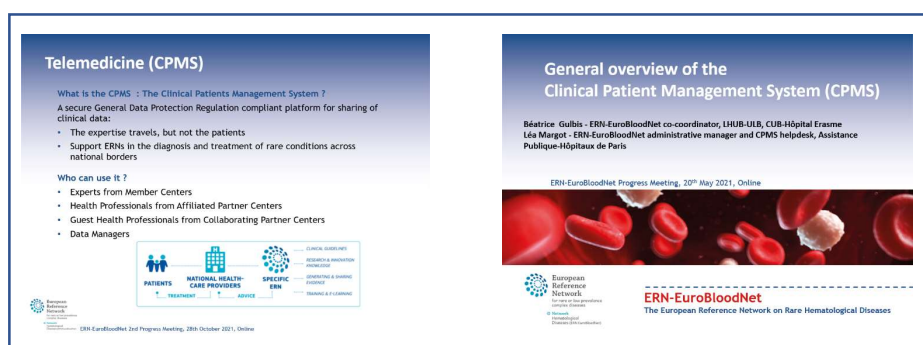


Pic. 1. Piece of news for the end of the “Connecting EuroBloodNet II” project, News section on ERN-EurobloodNet website

Dedicated sessions at ERN-EuroBloodNet meetings

ERN-EuroBloodNet's presentations on CPMS in 2021 had an aim to present an overview of the platform and explain its rationale to health care professionals among ERN-EuroBloodNet's community. Due to the Covid-19 pandemic, online presentations were promoted:

- ERN-EuroBloodNet Webinar for Patients organizations : How to connect patients in Europe to Cutaneous Lymphoma experts via the ERN, 26th April 2021, Online
- ERN-EuroBloodNet Progress Meeting, 21st May 2021, Online
 - “General overview of the Clinical Patient Management System” provided by B.Gulbis and L.Margot
 - “The Experience of Cutaneous Lymphoma Virtual Boards” provided by M. Vermeer and U. Wehkamp
- ERN-EuroBloodNet 2nd Progress Meeting, 28th October 2021, Online
 - “Focus on EuroBloodNet actions for Cutaneous Lymphoma”, with a dedicated section for the CPMS Virtual Board and results, provided by M. Bagot and N. Bolaños



Pic.2. Examples of presentations on CPMS delivered by EuroBloodNet in 2021.

NEW CPMS DIRECT BUTTON AT ERN-EUROBLOODNET WEBSITE

ERN-EuroBloodNet website is the main door of dissemination of the activities and results to the RHD community. Accordingly its continuous update is cornerstone for reaching the critical mass of relevant actors in the different actions undertaken by the network.

[CPMS dedicated section](#) at the ERN-EuroBloodNet website provides the key information on the CPMS and training materials previously produced to promote and facilitate the use of the platform, available through the different subsections: [About CPMS](#), [How to use CPMS](#), [Find experts for panels](#).

In an effort to facilitate the direct access to CPMS, a direct button has been implemented at the footer of the website for a more visual engagement of the website users.



Pic.3. Direct buttons implemented at the footer of the web

2.2 ACTIONS ADDRESSING INCREASE IN COUNTRY COVERAGE

Up-to-date, the CPMS is mostly used among members of the ERNs, nationally recognized centers of expertise.

Efforts have been allocated to promote the use of the platform in those countries where representation of ERNs is not available, and thus, expertise may be lacking.

In this context ERN-EuroBloodNet has expanded its coverage from January 2022 through the inclusion of new full members and affiliated partners. As a result, ERN-EuroBloodNet has scaled-up the EU dimension of its actions by significantly increasing the number of HCPs and MS coverage with a total of 96 members from 18 MS, and 7 Affiliated Partners (APs) from 6 MS, allowing their full participation in the CPMS.

2.3 ACTIONS ADDRESSING INCREASE IN DISEASE COVERAGE

As described in the previous report the actions focused on very rare disease have been prioritized to allow the micromapping of the expertise available at the EU level. Therefore ERN-EuroBloodNet continue developing the actions below:

Integration of new members in the online repository of members and experts:

The resolution of the Assessment of the call for new ERNs members has allowed the integration of 36 new ERN-EuroBloodNet members. Accordingly, their new profiles for Healthcare providers, Departments and Experts (representatives, substitutes and Multidisciplinary teams) have been created on the [ERN-EuroBloodNet website](#) and are searchable through the [search tool](#)

Expansion and upgrade of ERN-EuroBloodNet experts profiles:

Considering the wide range of prevalences in which RHD disorders are presented, special efforts have to be devoted for the identification of experts on very rare diseases whose highly specialized expertise may still be available in other European centers that are not part of the official ERNs Board of Members or APs and which participation represents a high added value on these precise actions undertaken by the network, as could be their participation on CPMS panels.

Accordingly, in the frame of the Connecting EuroBloodNet II, the repository was further upgraded for the creation of the [Supporting Partners](#), as expert profiles on very concrete ultra-rare disorders out of Members and APs whose highly specialized expertise is of high added value, while allowing their searchability to participate in CPMS or other very concrete network actions. The design ensures the same structure as for the creation of ERN-EuroBloodNet Members profiles, including the selection of the diseases of expertise based on ORPHA classification.

Creation of CPMS Virtual Boards:

This action results in formation of Virtual Boards of international experts representing very rare disorders, registered in CPMS and meeting for online regular cross border consultation. This initiative allows to cover geographical gaps, providing the tool for medical consultation between experts and health professionals from the countries where expertise on particular very rare disorders is missing.

This action was launched for the area of Cutaneous Lymphoma under the Connecting EuroBloodNet II grant and is being expanded under the currently ongoing Connecting EuroBloodNet III.

4. RESULTS

LINKED TO TASK 1. ANALYSIS OF ERN EUROBLOODNET CPMS ACTIVITY BASED ON PERFORMANCE INDICATORS

1.1 ERN-EUROBLOODNET ACTIVITY REPORT

Up to date 20th of February 2022, a total number of **43** panels have been created for RHDs since the launch of the CPMS, from which 21 are closed now with an outcome report produced and delivered to patient. 4 panels were archived and 2 was aborted due to technical issues. According to the ERN Activity Report for the date 20th of February 2022 which is generated automatically by the CPMS (there is no option to adjust the date) ERN-EuroBloodNet has **100** registered users from which **78** are active.

As in the case of the previous report, we observe slight differences between the numbers of active users, which was already reported to the EC officers. These differences might be due to different algorithms used in these platforms for data analysis. For the status of CPMS consultations: EuroBloodNet's CPMS users have opened **43** panels on single patients' cases. The 31 of them passed the step of panel selection, 25 of them the data completion, 23 of them the assessment, 19 of them as already produced the outcome report and the same 22 were already signed off and closed. Table 1 summarizes the report of activity.

ERN Activity Report Sun, 20 Feb, 2022

Weekly Monthly Quarterly Yearly Total

CPMS Activity

	Registered Users	Active Users	Number Of Panels Newly Created	Number Of Panels
	Total	Total	Total	Total
EuroBloodNet	100	78	43	43

CPMS Panel Stage

	Open	Panel Selection	Data Completion	Assessment	Outcome	Sign-Off	Closed	Archive	Aborted
	Total	Total	Total	Total	Total	Total	Total	Total	Total
EuroBloodNet	43	31	25	23	19	22	21	4	2

Tab.1. Total CPMS activity for EuroBloodNet until 20.02.2021

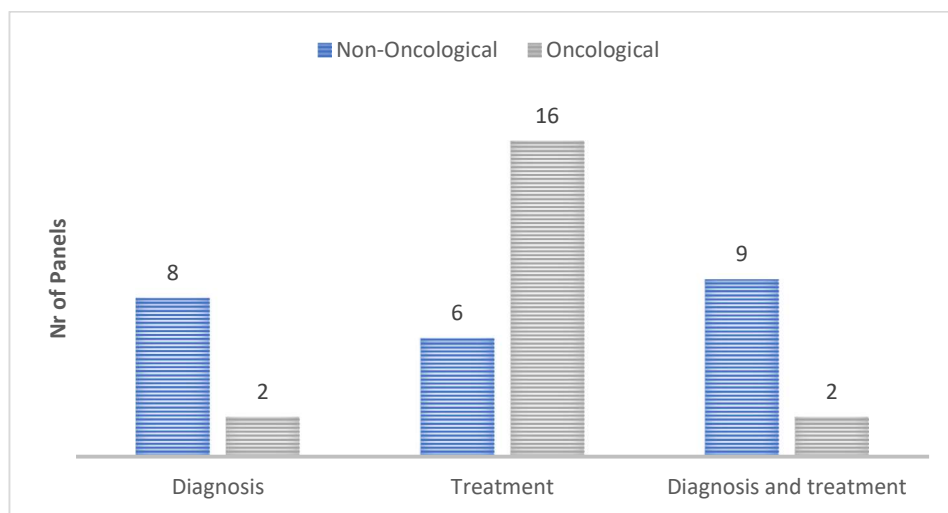
The number of active users is defined as a count of users that have logged on that month and effected any change to the database or written to the system, Table 2 summarizes the distribution of sub-thematic areas chosen in the profile by active users. The 43 cases entered to the CPMS can be analyzed according to the 9 thematic areas the consultation was focused on: Congenital dyserythropoietic anemia, Blackfan-Diamond anemia, Acquired BMF and Inherited BMF, Hereditary erythroenzymopathies and RBC membrane defects, Haemoglobinopathy, Rare lymphomas, Myeloproliferative neoplasm (MPN), Haemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis and Myelodysplastic syndrome (MOS). Accordingly, the Table 3 shows the thematic areas and advice required and Graph 1 number of panels by type of advice and oncological or non-oncological hub for the panels opened until the 20.02.2022 provided by the EuroBloodNet CPMS activity report.

Sub-thematic areas (HP of different subnetwork might be registered in different categories)	Number of active users registered
Amyloidosis	15
Congenital dyserythropoietic anemia, Blackfan-Diamond anemia, Acquired BMF and Inherited BMF	33
Haemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis	34
Haemoglobinopathy	40
Haemophilia A, B, The rarer congenital deficiencies of other coagulation factors, Von Willebrand disease, inherited platelet defects	26
Hereditary erythroenzymopathies and RBC membrane defects	36
Myelodysplastic syndrome (MOS)	27
Myeloproliferative neoplasm (MPN)	21
Rare lymphomas	30

Tab. 2. Number of active users registered to subthematic areas report for 20.02.2022

Thematic areas	Diagnosis	Treatment	Diagnosis & treatment	Total
Congenital dyserythropoietic anemia, Blackfan-Diamond anemia, Acquired BMF and Inherited BMF	2	2	1	5
Hereditary erythroenzymopathies and RBC membrane defects		1	1	2
Haemoglobinopathy	1		2	3
Rare lymphomas	1	1		2
Myeloproliferative neoplasm (MPN)	1	4	2	7
Haemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis	3	2	6	11
Myelodysplastic syndrome (MOS)		1		1
Haemophilia A, B, the rarer congenital deficiencies of other coagulation factors, Von Willebrand disease, inherited platelet defects	8	12	0	31

Tab. 3. Panels by thematic area and advice required report until 20.02.2022



Graph 1. Number of panels by type of advice and oncological or non-oncological hub report until 07.02.2021.

1.2 ANALYSIS OF PANELS CREATED IN 2021

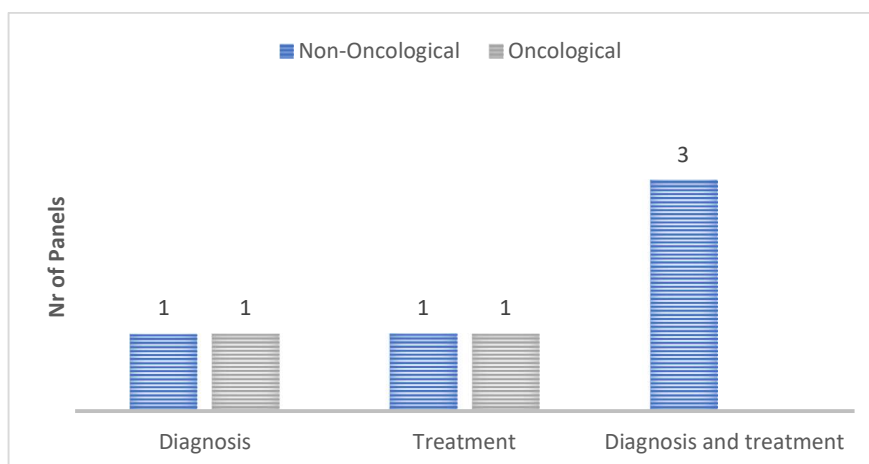
For the period from the 1st of January 2021 until 31st December 2021, to the EuroBloodNet's CPMS were enrolled 7 patients and consequently opened 7 panels. The highest number of panels entered have been for the Diagnosis and Treatment - 3 - 1 in the field of Congenital dyserythropoietic anemia, Blackfan-Diamond anemia, Acquired BMF and Inherited BMF, one Haemoglobinopathy, and one in Hereditary erythroenzymopathies and RBC membrane defects. The distribution of the cases created in 2021 is presented in the Table 4.

Thematic area	Diagnosis	Treatment	Diagnosis & treatment	Total
Congenital dyserythropoietic anemia, Blackfan-Diamond anemia, Acquired BMF and Inherited BMF			1	1
Haemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis	1			1
Haemoglobinopathy			1	1
Myelodysplastic syndrome (MOS)	1	1		2
Hereditary erythroenzymopathies and RBC membrane defects		1	1	2
Total	2	2	3	7

Tab. 4. Panels by thematic area and advice required opened between 1st of Jan 2021 and 31st of Dec 2021.

If compile the panels according to the oncological and non-oncological diseases, a quite equal distribution can be observed based on the needs of the advice required. Over the 5 non-oncological panels open in 2021, 3 requested advice in both Diagnosis and treatment, 1 only for diagnosis and 1 only for treatment. Regarding the 2 oncological panels that have been opened: 1 requested advice for treatment while the other requested advice for diagnosis.

Graph 1 summarizes the requests for diagnosis and treatment for oncological and non-oncological diseases between 1st of January 2021 and 31st December 2021.



Graph 2. Number of panels by type of advice and oncological or non-oncological hub in 2021.

LINKED TO TASK 2. ERN-EUROBLOODNET STRATEGY FOR PROMOTING THE WIDE IMPLEMENTATION OF THE CPMS

As result of the different actions addressing the increase of awareness on the CPMS, the following results have been obtained:

2.1 ANALYSIS OF THE NUMBER OF USERS AND PANELS OVER THE LAST FOUR YEARS

The growth of number of newly registered users for (9 in 2021), indicates that EuroBloodNet's actions managed to activate already registered users by providing them technical support and guiding them through the platform. As a result, in 2021 a number of 7 panels were opened along which 2 have already been closed. Table 5 presents the yearly reports of ERN-EuroBloodNet CPMS activity and Graphs 3 and 4 summarizes its outcomes.

A slight decrease can be observed in the number of newly opened panels that can be partially explained by the impact of some human resources changes issued in 2021 at the level of the ERN coordination team. The ongoing recruitment process for hiring a new dedicated CPMS project manager might help to boost the current trend. Secondly, the current version of the CPMS have been updated at the end of the year 2021 offering more clarity and fluidity in the CPMS workflow that could help users in their daily use of the platform. The new CPMS pilots and virtual boards that are under construction for the new ERN-EuroBloodNet period of implementation will enable the development of new collaboration between health professionals on specific diseases that will certainly lead to the dynamization of the overall CPMS activity.

CPMS Activity

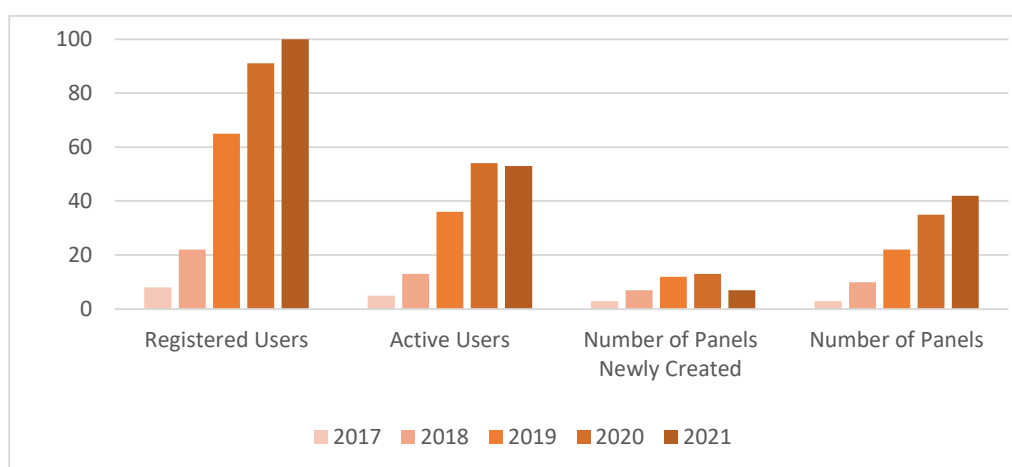
	Registered Users						Active Users						Number Of Panels Newly Created						Number Of Panels					
	2017	2018	2019	2020	2021	2022	2017	2018	2019	2020	2021	2022	2017	2018	2019	2020	2021	2022	2017	2018	2019	2020	2021	2022
EuroBloodNet	8	22	65	91	100	100	5	13	36	54	53	15	3	7	12	13	7	1	3	10	22	35	42	43

CPMS Panel Stage

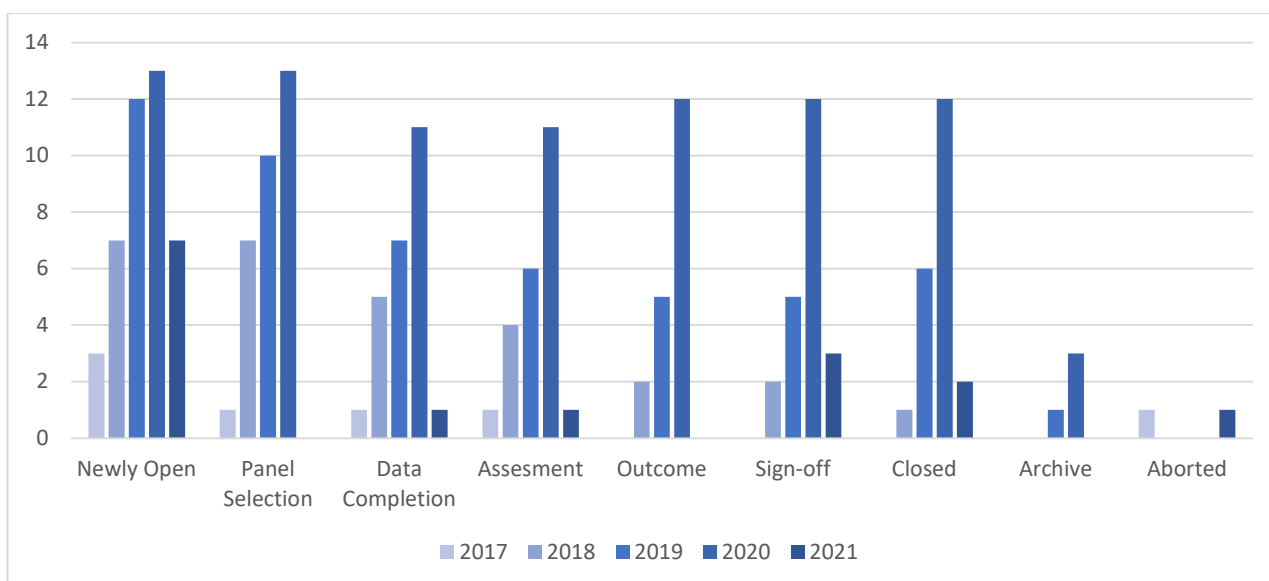
	Open						Panel Selection						Data Completion						Assessment					
	2017	2018	2019	2020	2021	2022	2017	2018	2019	2020	2021	2022	2017	2018	2019	2020	2021	2022	2017	2018	2019	2020	2021	2022
EuroBloodNet	3	7	12	13	7	1	1	7	10	13	0	0	1	5	7	11	1	0	1	4	6	11	1	0

Outcome						Sign-Off						Closed						Archive						Aborted					
2017	2018	2019	2020	2021	2022	2017	2018	2019	2020	2021	2022	2017	2018	2019	2020	2021	2022	2017	2018	2019	2020	2021	2022	2017	2018	2019	2020	2021	2022
0	2	5	12	0	0	0	2	5	12	3	0	1	6	12	2	0	0	0	1	3	0	0	0	1	0	0	0	1	0

Tab. 5. Yearly CPMS activity for ERN-EuroBloodNet until February 2022.



Graph 3. Yearly report on EuroBloodNet's CPMS activity.



Graph 4. Yearly report on EuroBloodNet's CPMS Panel Stage.

2.2 INCREASE IN COUNTRY COVERAGE

In 2021, the geographical coverage of EuroBloodNet's CPMS was enriched by the representation of Malta with 3 new CPMS activated users.

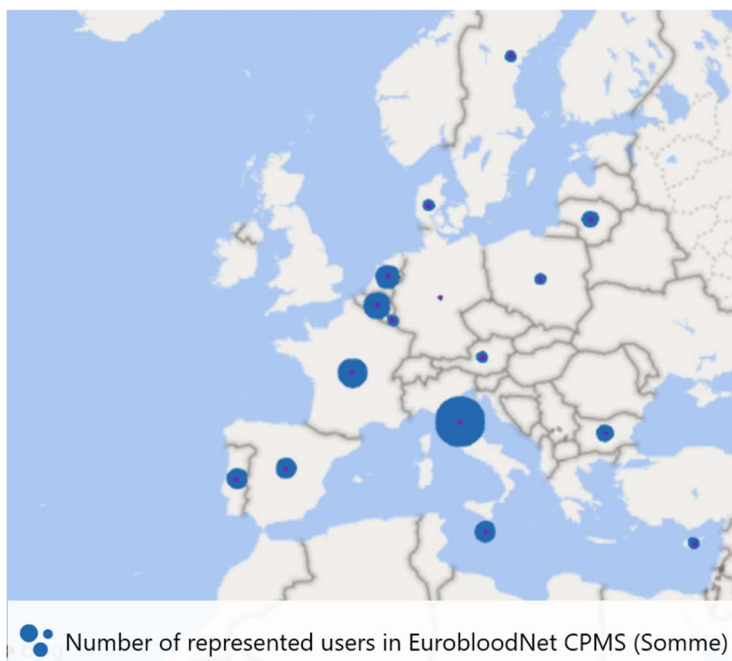
The following table 6 summarizes the number of registered users per country, accounting only those with an active account in SAAS authorization system (tool for the management of authorization requests from CPMS users). A mapping view of this repartition (See Pic. 4) highlights some remaining gaps in the disease coverage especially in the central-Balkan Europe.

Country	Number of represented users in EurobloodNet CPMS	Number of users with active account in SAAS
Austria	1	1
Belgium	5	4
Bulgaria	2	3
Cyprus	1	1
Denmark	1	1
France	6	9
Germany	0	4
Italy	17	17
Lithuania	2	2
Luxembourg	1	1
Malta (New)	3	4
Netherlands	4	4
Poland	1	1
Portugal	3	3
Spain	3	5
Sweden	1	1
Total	51	61

Tab.6. EuroBloodNet's status of users in CPMS per country

The numbers for this analysis were extracted directly from SaaS authorisation platform based on status of users' accounts (value ACTIVE), and directly from the list of registered users in CPMS included in the section Performance Indicators, based on the activity of the user (value TRUE). To increase the geographical coverage and therefore the accessibility to the CPMS ERN-EuroBloodNet opens a possibility for registration in CPMS not only for Members but also for Affiliated Partners with the same procedures and roles as full members, and Guest Experts from the Collaborating Centres (not officially recognized as Members) - these users have guest role with some administrative restrictions.

The action of increased geographical coverage will be continued and promoted in regards to the new Members Call 2019 resulting in the ongoing incorporation of additional 36 HCPs, with a potential new CPMS users representing lacking countries and giving the access to online and cross border medical consultation in the field of rare haematological diseases.



Pic. 4. Number of represented users In EuroBloodNet CPMS

2.3 INCREASE IN DISEASE COVERAGE

In 2020 the pilot project to build a model for efficient cross border CPMS consultation was created in the frame of Connecting EuroBloodNet II, establishing the CPMS Virtual Board on Cutaneous Lymphoma. The aim of it is to use the established strategy to promote CPMS Virtual Boards in other rare hematological disorders networks to unable non-experts centers to submit cases to these Virtual Boards and to benefit their expertise when expertise is lacking at their center and/or national level.

Accordingly two additional disease groups have been identified for the expansion of the Virtual Board model under the frame of Connecting EuroBloodNet III, including Red Blood Cell, Myelodysplastic Syndromes.

Lastly, the recent conduction of the ERN-EuroBloodNet European mapping of highly specialized procedures for primary vitreo-retinal lymphoma has allowed the identification of important disparities in clinical practice between physicians on diagnosis, treatment and assessment of treatment response and follow up, and the creation of a Virtual Board group for specifically discussing these disorders within the CPMS has been one of the potential outcomes from this network. Further details can be found at Deliverable 4.5 ERN-EuroBloodNet report on the availability of highly specialized procedures for rare hematological diseases 2 (February 2022) and the peer review publication "[Primary vitreoretinal lymphoma: short review of the literature, results of a European survey and French guidelines of the LOC network for diagnosis, treatment and follow-up](#)" published in Current opinion in oncology in September 2021 with the acknowledgement of ERN-EuroBloodNet.

5. CONCLUSIONS AND NEXT STEPS

The CPMS can play a crucial role in covering important gaps in the field of ultra-rare diseases resulting from their low prevalence: non-existing highly secured online infrastructure for experts to exchange the knowledge and medical advice cross borders, non-equal access to highly specialized medical tools across European countries, lack of centralized repository of expertise. But the task of the wide implementation of the CPMS is a challenging process requiring well defined and adjustable strategy.

ERN-EuroBloodNet's strategy is built on multiple channels of action: 1) CPMS promotion, 2) geographical coverage, and 3) disease coverage. The first action including working on increase of awareness and ensuring training of health professional for facilitating the use of the CPMS (through updated online guides, or virtual personal trainings). The second action aims at increasing the number of countries represented in CPMS but enabling the access to the platform not only to the Member HCPs but also to Affiliated Partners and Guest Centres. The action of increased geographical coverage will be continued and promoted in regards to the incorporation of new 36 HCPs members of ERN-EuroBloodNet, with a potential new CPMS users representing lacking countries and giving the access to online and cross border medical consultation in the field of RHD. Lastly, the third action focuses on revision of ORPHA classification for very rare diseases, publishing the ERN-EuroBloodNet experts' profiles online and developing Virtual Board of experts in ultra-rare diseases in order to increase the disease coverage by the EuroBloodNet's CPMS.

Based on the results described in this report, it can be concluded that above strategies obtained by the network bring positive results such as increase number of new CPMS users and of the disease coverage.

Nevertheless, the promotion of the CPMS within and outside ERN-EuroBloodNet especially at the national and local level is paramount to ensure its efficient use and wider outreach among the rare hematological diseases health professionals. Aligned to this approach it is crucial for ERN-EuroBloodNet to continue the promotion of the platform among and outside of the ERN community, and to keep strong collaboration between users and CPMS Helpdesk to overtake technical obstacles in by:

- a) Regular organization of the CPMS workshops and dissemination of the invitations among EuroBloodNet's CPMS users
- b) Management of CPMS panels and video meetings by the EuroBloodNet's Helpdesk
- c) Promotion of the CPMS among RHD stakeholders, for example ERN-EuroBloodNet Newsletter, Twitter, Facebook and LinkedIn profiles
- d) Promotion of the CPMS among health care professionals and patients organizations

In addition, the effective use of the CPMS will be ensured through the different actions performed under Connecting EuroBloodNet III, as:

a) Maintenance and consolidation of the role of ERN-EuroBloodNet CPMS Help Desk as the main contact point for technical assistance : It provides support at registered CPMS users and new users who would like to contribute to the consultations in CPMS. CPMS Manager provides support through the Helpdesk based on: a) providing technical support after the request of the user, and b) promoting and creating practical user guides. Additionally, the feedback from the CPMS users will be gathered in order to identify and understand the needs for improvement.

b) Promoting ERN-EuroBloodNet Virtual Boards for CPMS in very rare diseases committed to consult patients cases on regular basis. Three groups of diseases have already been identified for this initiative, with the first one Cutaneous Lymphoma as a pilot project.

Finally the ERN-EuroBloodNet will implement during the next period of implementation pilot schemes to provide economical support for HCPs opening the case consultations in the CPMS. Three pilot schemes are envisaged for three CPMS Virtual Boards focused on ultra rare diseases. Nevertheless, the opening of panels besides the disease focused Virtual Boards will be continuously promoted and will be eligible for the pilot scheme remuneration.



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



www.eurobloodnet.eu

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