



## DELIVERABLE 7.2 CPMS ACTIVITY BY ERN-EUROBLOODNET MEMBERS

**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

### DELIVERABLE 7.2 CPMS ACTIVITY BY ERN-EUROBLOODNET MEMBERS

Report Document

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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 2249 active users, created 1700 panels for consultation, and successfully closed 849 patients cases (according to the ERN Status report January 2021).

#### 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 supporting 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 triple 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”, actions funded by the call CEF TELECOM CALLS FOR PROPOSALS 2018 CEF-TC-2018-4 for 'Connecting EuroBloodNet II' (2018-EU-IA-0191, 01/10/2019-31/03/2021) aims to a) promote the wide implementation of the CPMS while ensuring its efficient use, b) scale up the actions initiated under “Connecting EuroBloodNet” 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 and II 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:

#### New and updated One-page CPMS guides

ERN-EuroBloodNet CPMS website section was created during the previous period of the network implementation. It contains different topics giving overview of the CPMS:

- [About CPMS section](#) with general information on the objectives and utilities of the platform and ERN-EuroBloodNet helpdesk as well as direct link to the CPMS.

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

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

- [Find experts for panels section](#) with a link to ERN-EuroBloodNet's inventory of members and experts depends on the profile and field of expertise, and a search tool for easier identification.

Following the experience based on technical support requests from users, and technical issues during CPMS registration and first steps within the platform, EuroBloodNet identified the need to create updated and new simplified versions of step-by-step guides.

The new and updated one-page CPMS guides can be found at the section of '[How to use the CPMS](#)' including the following 4 new one page guides on account activation, first login to CPMS, patient enrollment and opening a panel, and on video meeting in CPMS:



Pic.1. One-page CPMS guides.

- [One-page CPMS account activation guide](#)
- [One-page first login to CPMS guide](#)
- [One-page how to enrol patient an open a panel guide](#)
- [One-page video meeting in CPMS guide](#)

## Online bulletins

To support new users or experts involved in CPMS Virtual Boards dedicated emails were sent to ERN-EuroBloodNet members' experts, affiliated partners and guest experts including

- CPMS objectives
- Introduction on its use
- Brief steps on how to create an EU Login and to request access to the CPMS
- Link to technical support section on the EuroBloodNet's website or invitation to join the workshop on CPMS

In addition, a piece of news were created on initiatives correlated with EuroBloodNet's CPMS including the formation of Virtual Board in Cutaneous Lymphoma (initiative developed under the Connecting EuroBloodNet - II grant) and publication of the updated versions of guides. This information was also shared on EuroBloodNet's social media channels: [Facebook](#), LinkedIn, Twitter

- [EuroBloodNet's initiatives for Cutaneous Lymphoma community in 2020](#)
- [The first EuroBloodNet's Cutaneous Lymphoma Virtual Board online clinical meeting in CPMS has taken place!](#)
- [Four new "One-page guide" documents to support the use of CPMS available at EuroBloodNet's How to use CPMS section!](#)

## Dedicated sessions at ERN-EuroBloodNet meetings

EuroBloodNet's presentations on CPMS in 2020 had an aim to present an overview of the platform and explains its rationale to Health care professionals among EuroBloodNet's community. Due to the Covid-19 pandemics, EuroBloodNet promoted online presentations.

- CPMS Clinical Patient Management System, Dr Julia Dominika Zajac, the 4th EuroBloodNet Board of Network Meeting, 22nd of October 2020
- CPMS Cutaneous Lymphoma, Prof Maarten Veermer, the 4th EuroBloodNet Board of Network Meeting, 22nd of October 2020
- Meeting on Virtual Board in CPMS for Cutaneous Lymphoma, Dr Julia Dominika Zajac, Meeting with Cutaneous Lymphoma Experts, 7th of April 2020





Pic.2. Presentations on CPMS delivered by EuroBloodNet in 2020.

## 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 through the inclusion Affiliated Partners in those countries where there were no previous official members, allowing their participation in the CPMS with the same procedures and roles as full members without the need of guest role.

## 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 EuroBloodNet continue developing the actions below:

1. Revision of ORPHA classification for very rare diseases: Existing codifications usually are lacking for the very rare disorders, as per the case of Haemochromatosis and iron metabolism disorders. New codes defined will be proposed to ORPHA for the update of the classification.
2. Upgrade of ERN-EuroBloodNet experts profiles: An improvement has been performed in the profiles application form for the selection of the diseases aiming to a) facilitate their selection by the experts and b) expand the possibility of the selection of the diseases through all the levels available at ORPHA classification. In this way, the experts can be searched by concrete diseases through the [search tool](#) available at EuroBloodNet website, allowing the identification of potential experts to participate in the open panels.
3. Identification of ultra rare diseases networks which due to their orphan character lack proper telemedicine tools to exchange the knowledge and enable the access to medical consultation. 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 is developed under the Connecting EuroBloodNet II grant and will be described in details in the upcoming report.

## 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 07th of February 2021, a total number of 35 panels have been created for RHDs since the launch of the CPMS, from which 19 are closed now with an outcome report produced and delivered to patient. 4 panels were archived and one was aborted due to technical issues. According to the ERN Activity Report for the date 7th of Feb 2021 which is generated automatically by the CPMS (there is no option to adjust the date) ERN-EuroBloodNet has **93** registered users from which **72** 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 **35** 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 19 were already signed off and closed. Table 1 summarizes the report of activity.

ERN Activity Report Sun, 07 Feb, 2021

Weekly Monthly Quarterly Yearly Total

CPMS Activity

	Registered Users	Active Users	Number Of Panels Newly Created	Number Of Panels
	Total	Total	Total	Total
<b>EuroBloodNet</b>	93	72	35	35

CPMS Panel Stage

	Open	Panel Selection	Data Completion	Assessment	Outcome	Sign-Off	Closed	Archive	Aborted
	Total	Total	Total	Total	Total	Total	Total	Total	Total
<b>EuroBloodNet</b>	35	31	25	23	19	19	19	4	1

Tab.1. Total CPMS activity for EuroBloodNet until 07.02.2021

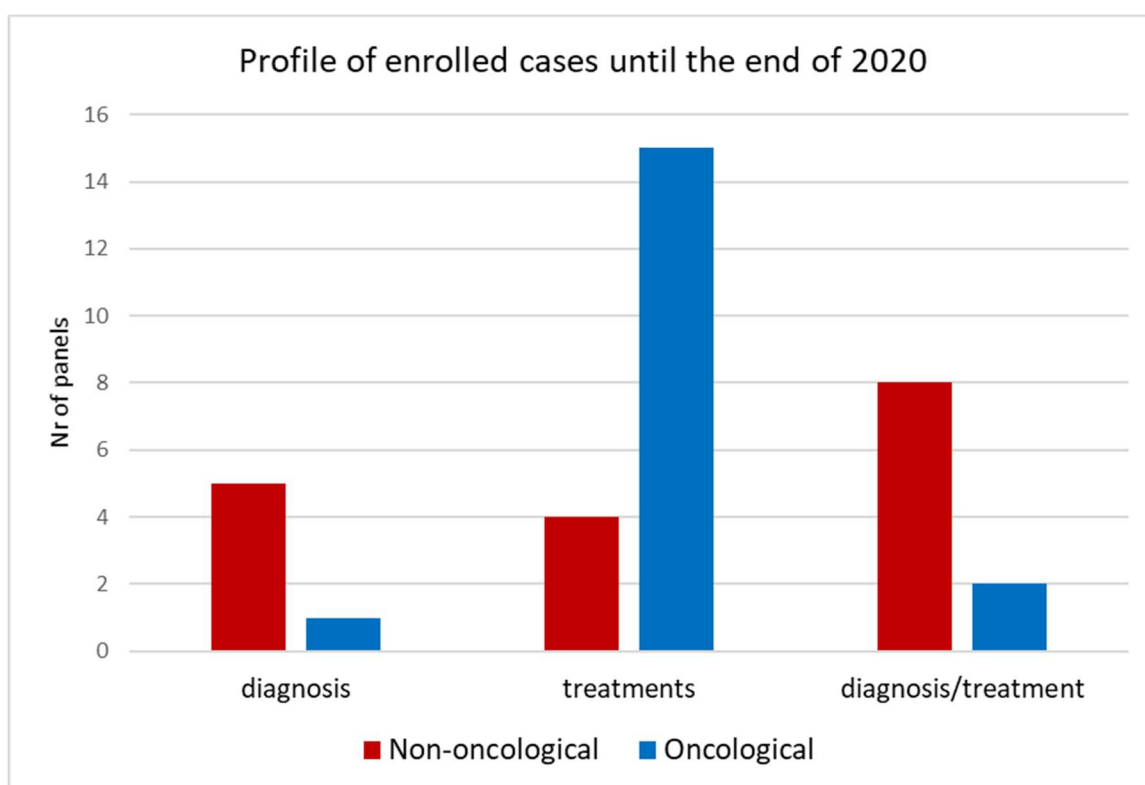
The number of active users is defined as a count of users that have logged on that month and effected any change to the database or written to the system, Table 2 summarizes the distribution of sub-thematic areas chosen in the profile by active users. The 35 cases entered to the CPMS can be analyzed 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 07.02.2021 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	<b>13</b>
CONGENITAL DYSERYTHROPOIETIC ANEMIA, BLACKFAN-DIAMOND ANEMIA, ACQUIRED BMF AND INHERITED BMF	<b>28</b>
HAEMOCHROMATOSIS AND OTHER RARE GENETIC DISORDERS OF IRON METABOLISM AND HEME SYNTHESIS	<b>30</b>
HAEMOGLOBINOPATHY	<b>34</b>
HAEMOPHILIA A, B, THE RARER CONGENITAL DEFICIENCIES OF OTHER COAGULATION FACTORS, VON WILLEBRAND DISEASE, INHERITED PLATELET DEFECTS	<b>23</b>
HEREDITARY ERYTHROENZYMOPATHIES AND RBC MEMBRANE DEFECTS	<b>30</b>
MYELODYSPLASTIC SYNDROME (MOS)	<b>24</b>
MYELOPROLIFERATIVE NEOPLASM (MPN)	<b>19</b>
RARE LYMPHOMAS	<b>26</b>

Tab. 2. Number of active users registered to subthematic areas report for 07.02.2021

THEMATIC AREA	DIAGNOSIS	TREATMENT	DIAGNOSIS AND TREATMENT	TOTAL
Congenital dyserythropoietic anemia, Blackfan-Diamond anemia, Acquired BMF and Inherited BMF		2	2	4
Hereditary erythroenzymopathies and RBC membrane defects	3		5	8
Haemoglobinopathy	1		1	2
Rare lymphomas	1	11		12
Myeloproliferative neoplasm (MPN)		1		1
Haemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis		1		1
Myelodysplastic syndrome (MOS)		3	2	5
Haemophilia A, B, the rarer congenital deficiencies of other coagulation factors, Von Willebrand disease, inherited platelet defects	1	1		2

Tab. 3. Panels by thematic area and advice required report until 07.02.2021



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

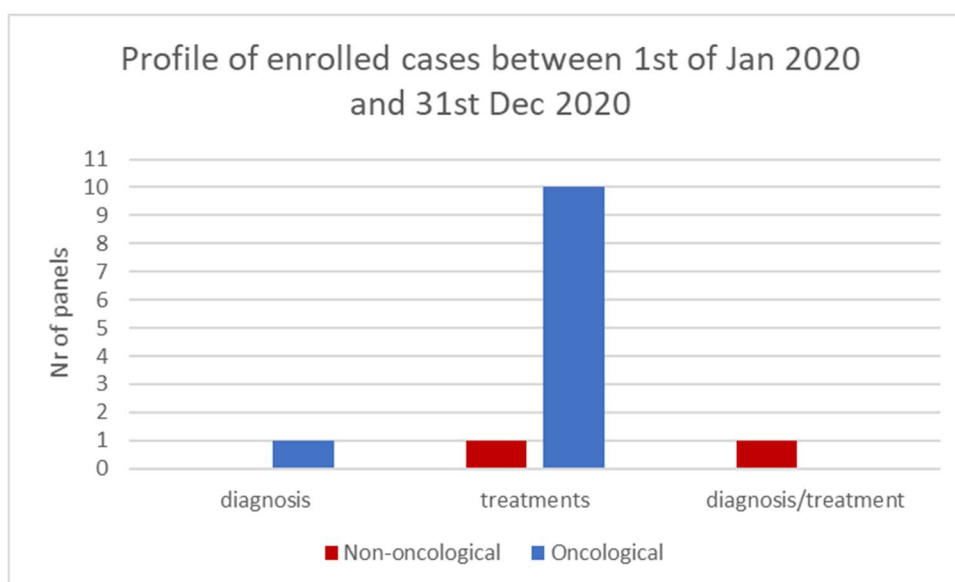
## 1.2 ANALYSIS OF PANELS CREATED IN 2020

For the period from the 1st of January 2020 until 31st December 2020, to the EuroBloodNet's CPMS were enrolled 13 patients and consequently opened 13 panels. The highest number of panels entered have been for the treatment - 11 - 9 in the field of Rare Lymphomas, and one per Haemophilia A, B, The rarer congenital deficiencies of other coagulation factors, Von Willebrand disease, inherited platelet defects, and Myelodysplastic syndrome (MOS). One case on diagnosis was related to field of Rare Lymphomas. The distribution of the cases created in 2020 is presented in the Table 4.

Thematic area	Diagnosis	Treatment	Diagnosis and treatment	Total
Rare lymphomas	1	9		10
Haemophilia A, B, The rarer congenital deficiencies of other coagulation factors, Von Willebrand disease, inherited platelet defects		1		1
Myelodysplastic syndrome (MOS)		1		1
Hereditary erythroenzymopathies and RBC membrane defects			1	1

Tab. 4. Panels by thematic area and advice required opened between 1st of Jan 2020 and 31st of Dec 2020.

Whereas, if compile the panels according to the oncological and non-oncological diseases, a significant difference can be observed based on the needs of the advice required. For the 13 cases entered, the biggest needs identified for oncological field was the treatment (9), then for diagnosis (1). For the non-oncological field the need was distributed equally resulting in one case submitted for the treatment and diagnosis/treatment. The results are correlated with the forming of pilot project on EuroBloodNet's Virtual Board of Experts in Cutaneous Lymphomas (rare lymphomas, oncological hub) - which results in regular clinical meetings in CPMS in 2020, where the ultra rare cases were submitted in order to provide cross border consultation among international experts. This project has been developed under the Connecting EuroBloodNet II grant and the overview will be presented in the following report. Graph 1 summarizes the requests for diagnosis and treatment for oncological and non-oncological diseases between 1st of January 2020 and 31st December 2020.



Graph 2. Number of panels by type of advice and oncological or non-oncological hub in 2020.

## 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 INCREASE IN NUMBER OF USERS AND PANELS OVER THE LAST FOUR YEARS

As a result of the EuroBloodNet's CPMS unified strategy the significant rise of the network activity in CPMS was observed, what fits in the growth trend which has been successfully achieved since the first year of CPMS usage showing that every year the number of active users increases almost in double-fold manner (from 6 to 14 to 36 and finally 60 in 2020).

The growth of number of newly registered users for 2020 - 26 in comparison to 2019 - 43, correlated with the increased activity of users 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 2020 a number of 13 panels were opened, 13 passed the step of panel selection, 11 of panel completion, 11 of assessment, 12 delivered the outcome report and were signed off, 12 were closed, 3 were archived and none were aborted. Table 5 presents the yearly reports of ERN-EuroBloodNet CPMS activity and Graphs 3 and 4 summarizes its outcomes.

ERN Activity Report Sun, 07 Feb, 2021

Weekly Monthly Quarterly Yearly Total

CPMS Activity

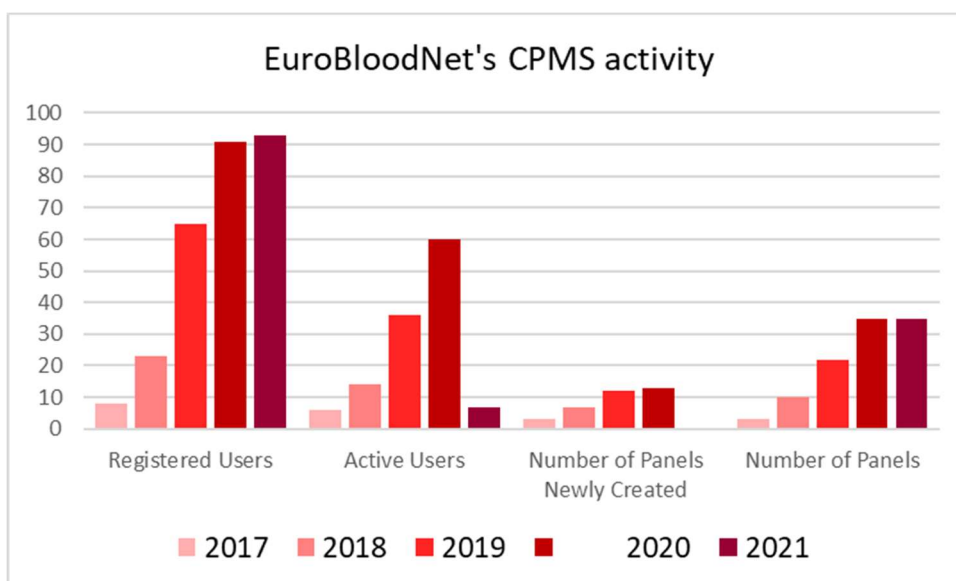
	Registered Users					Active Users					Number Of Panels Newly Created					Number Of Panels				
	2017	2018	2019	2020	2021	2017	2018	2019	2020	2021	2017	2018	2019	2020	2021	2017	2018	2019	2020	2021
<b>EuroBloodNet</b>	8	22	65	91	93	6	14	36	60	7	3	7	12	13	0	3	10	22	35	35

CPMS Panel Stage

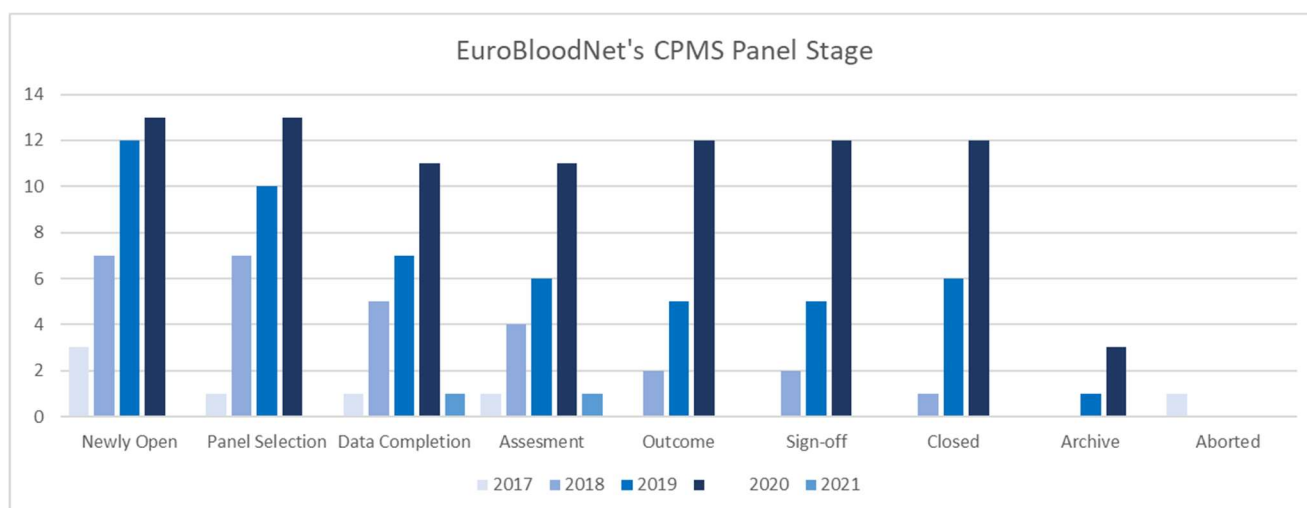
	Open					Panel Selection					Data Completion					Assessment					Out
	2017	2018	2019	2020	2021	2017	2018	2019	2020	2021	2017	2018	2019	2020	2021	2017	2018	2019	2020	2021	2017
<b>EuroBloodNet</b>	3	7	12	13	0	1	7	10	13	0	1	5	7	11	1	1	4	6	11	1	1

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

Tab. 5. Yearly CPMS activity for ERN-EuroBloodNet until 2021.



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 the previous year report for 2019 ERN-EuroBloodNet has informed about incorporation of new Affiliated partners, which have access to CPMS :

- 7 Associated National Centers: 2 Austria, 2 Denmark, 1 Estonia, 1 Hungary, 1 Slovakia
- 3 National coordination hubs: Malta, Luxemburg, Slovenia

As a result the geographical coverage of EuroBloodNet's CPMS was enriched by the representation of Austria and Luxemburg. Additionally to that, also health professionals from Poland and Sweden have joined the platform, which was a gap identified in the last year report.

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):

Previous annual report



Current status for EuroBloodNet CPMS

Country	NUMBER OF REPRESENTED USERS IN EUROBLOODNET CPMS	NUMBER OF USERS WITH ACTIVE CPMS ACCOUNT IN SAAS
Belgium	4	7
Bulgaria	1	2
Cyprus	1	1
Denmark	1	1
France	6	9
Germany	2	2
Ireland	1	1
Italy	13	22
Lithuania	1	2
Netherlands	3	6
Portugal	2	3
Spain	1	4
<b>United Kingdom</b>	1	1
	<b>37</b>	<b>61</b>

Country	NUMBER OF REPRESENTED USERS IN EUROBLOODNET CPMS	NUMBER OF USERS WITH ACTIVE CPMS ACCOUNT IN SAAS
<b>Austria</b>	1	1
Belgium	8	8
Bulgaria	2	2
Cyprus	1	1
Denmark	1	1
France	9	11
Germany	6	7
Ireland	0	1
Italy	22	24
Lithuania	2	3
<b>Luxembourg</b>	1	1
Netherlands	5	7
<b>Poland</b>	2	2
Portugal	4	4
Spain	5	5
<b>Sweden</b>	1	1
	<b>70</b>	<b>79</b>

Tab.6. EuroBloodNet's status of users in CPMS per country in comparison with the previous report

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 upcoming incorporation of additional 33 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.

## 2.3 INCREASE IN DISEASE COVERAGE

Three disease groups in the field of RHD have been already identified for the establishment of Expert Virtual Boards participating actively in the sharing of complex cases in the CPMS: Cutaneous Lymphoma, Red Blood Cell, Myelodysplastic Syndromes. This action is implemented in the context of the CEF-II grant Connecting EuroBloodNet-II.

In 2020 the pilot project was established to build a model for efficient cross border CPMS consultation based on the Cutaneous Lymphoma Virtual Board of Experts in CPMS. The aim of it is to use the established strategy to promote CPMS Virtual Boards in other rare hematological disorders networks and the implementation of this model started for the Red Blood Cell and Myelodysplastic Syndromes.



## 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.

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 production of new educational materials on CPMS in different formats. 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. While 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, increase value in active users, increase number of newly open panels, increased number of closed panels, which result in maintained growth trend of the EuroBloodNet's CPMS activity.

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 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 close collaboration with Connecting EuroBloodNet II grant, by:

- a) Consolidation the role of ERN-EuroBloodNet CPMS Help Desk as the main contact point for technical assistance
- b) Regular organization of the CPMS workshops and dissemination of the invitations among EuroBloodNet's CPMS users
- c) Management of CPMS panels and video meetings by the EuroBloodNet's Helpdesk
- d) Promotion of the CPMS among RHD stakeholders, for example ERN-EuroBloodNet Newsletter, Twitter, Facebook and LinkedIn profiles
- e) 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 II, as:

- a) Implementation of customized data set for ERN-EuroBloodNet.
- b) Establishment of CPMS Virtual Boards of Experts in very rare diseases committed to consult patients cases on regular basis. Three groups of diseases were identified for this initiative, with the first one Cutaneous Lymphoma as a pilot project:
  1. Cutaneous Lymphoma disorders
  2. Myelodysplastic Syndromes
  3. Red Blood Cell - Haemolytic Anaemia





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



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

Co-funded by the European Union

