



7.1 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

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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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TABLE OF CONTENTS

1. Introduction

- European Reference Networks and the Clinical Patient Management System
- ERN-EuroBloodNet Operational Helpdesk

2. Objectives

3. Methods

Task 1. Analysis of ERN-EuroBloodNet CPMS activity based on performance indicators

Task 2. ERN-EuroBloodNet strategy for promoting the wide implementation of the CPMS

2.1 CPMS Promotion and increase of awareness

CPMS Operational Helpdesk section at ERN-EuroBloodNet website

Informative bulletins

Dedicated sessions at ERN-EuroBloodNet face to face meetings and European/National Congresses

Organization of CPMS working days

2.2 Actions addressing increase in country coverage

2.3 Actions addressing increase in disease coverage

4. Results

Linked to Task 1. Analysis of ERN-EuroBloodNet CPMS activity based on performance indicators

1.1 ERN-EuroBloodNet Activity Report

1.2 Analysis of panels created in 2019

Linked to Task 2. ERN-EuroBloodNet strategy for promoting the wide implementation of the CPMS

2.1 Analysis of the increase in number of users and panels over the last three years

2.2 Increase in country coverage

2.3 Increase in disease coverage

5. Conclusions and Next steps

1. INTRODUCTION

INTRODUCTION OF THE CURRENT SITUATION OF THE CPMS

European Reference Networks and the Clinical Patient Management System

Set-up under the 2011 Directive on Patient Rights in Cross-Border Healthcare, European Reference Networks (ERNs) are virtual networks bringing together medical specialists across Europe to tackle rare or complex diseases and conditions that require highly specialized healthcare and a concentration of knowledge and resources. For the first time, a formal structure of voluntary collaboration between healthcare providers across the EU has been created for the direct benefit of the patient.

The first 24 thematic networks include over 900 highly specialized healthcare units located in more than 300 hospitals of 25 EU countries plus Norway and cover a wide range of disease groups that became operational in March 2017.

Healthcare providers who are members of ERNs are connected through a dedicated IT platform and, using a variety of telemedicine tools, offer access to expertise and knowledge of multidisciplinary teams, enabling patients suffering from such conditions to receive the best advice for treatment and diagnosis. A fundamental principle of the ERNs is the stipulation that knowledge should travel rather than patients (with an exception of few cases where patients may be referred for treatment in another country). Research is another key element of the ERNs providing a structured framework for joining research efforts across countries, thereby creating a knowledge hub, facilitating translational research and the development of good practice guidelines for diagnosis and care, and supporting cross-border registries. By gathering and analysing a large pool of patient cases, ERNs should contribute to observational studies and clinical trials, leading to new insights into RD and new drug therapies with potentially far-reaching benefits for patients.

In this context, the European Commission DG SANTE has provided ERNs with the Clinical Patient Management System (CPMS), a secure web-based application to support the networks in two core tasks:

1. Bringing expert specialised care to all patients in Europe the diagnosis and treatment of rare or low prevalence complex diseases or conditions across national borders: The system allow for virtual consultation across national borders, ensuring that the needed expertise can travel to the patient, instead of the other way around.
2. Keeping de-identified information on clinical data in a registry: to improve future knowledge on RDs, a database will be created with de-identified data of the cases introduced in the system.

In order to be included in the software application, the patient must give explicit and unambiguous consent to his healthcare provider. This consent form has three boxes: the first concerns consent for sharing data, the second is about consent on the inclusion in the database and the third is about the possibility to be contacted for research purposes. Patients must sign directly either in the box providing 'I consent' or in the box entitled 'I do not consent'.

First version of the CPMS was released on November 20th, 2017 and a pilot phase was undertaken until March 2018. During this first phase all ERNs familiarised themselves with the system in order to assure optimal functionality. After the pilot phase, the CPMS became available for healthcare providers outside ERNs to consult the highly specialised experts within ERNs.

ERN-EuroBloodNet Operational Helpdesk

ERN-EuroBloodNet encompasses more than 450 Rare Hematological Diseases (RHD) which are very heterogenous in their nature and clinical course e.g. oncological vs non-oncological, acute vs chronic or hereditary vs acquired. Accordingly, customization of CPMS is essential to ensure the efficient use of the platform in terms of technical requirements addressing the RHD needs.

As main action funded under 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), ERN-EuroBloodNet Operational helpdesk manager was hired in November 2018 in the co-coordinator centre of the network, CUB-Hôpital ERASME, Brussels, as the bridge between the users in HCPs and the Core services IT engineers supporting the communication and understanding between them. At the same time, being in charge of promoting the use of the Core platforms by ERN-EuroBloodNet Members and playing a key role in the clinical / case management aspects related with organisation and support to Clinical Virtual Meetings. Manager was responsible of user guidance and support regarding the planning, preparations of the panels, training for the use of information systems, follow-up of incidents related to information systems organization of the reporting, follow-up of user requests and bug reports with the core helpdesk.

As a result of the action the ERN-EuroBloodNet Operational Helpdesk was set up including the following major outcomes:

- 1) Establishment of an operational Helpdesk line: The operational helpdesk was established playing a pivotal role for: a) Promoting the use of the platform, b) support the users with the different barriers found.
- 2) Identification of technical specification requirements for ECP and CPMS customization according to ERN-EuroBloodNet needs based on an exploratory exercise for the identification of transversal technical specifications required for the CPMS customization according to ERN-EuroBloodNet needs.

In continuation with the outcomes achieved under “Connecting EuroBloodNet”, actions funded under 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 CPMS activity in the context of ERN-EuroBloodNet based on performance indicators
- To implement ERN-EuroBloodNet strategy to promote the use of CPMS use among the network members and non members for inter-professional consultation of complex cases, allowing the increase of number of users, panels, and expansion in terms of country and disease coverage

3. METHODS

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

Performance Indicators are the direct Index for activity of ERN-EuroBloodNet CPMS. This section is accessible only for the CPMS user with co-ordinator role.

It presents the results in the form of reports on users registration, active users, number of panels newly created (depends on the time frame), total number of panels, and panel stage: number of panel selections, data completion, assessments, outcomes, sign-offs, closed panels, archive and aborted.

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

2.1 CPMS PROMOTION AND INCREASE OF AWARENESS

Promotion of the CPMS within and outside ERN-EuroBloodNet is paramount to ensure its efficient use and wider outreach among the rare hematological diseases health professionals requiring advice for a complex case or willing to provide advice on complex cases of their expertise.

In close collaboration with Connecting EuroBloodNet I and II grants, dedicated efforts have been focused on increasing the awareness on the CPMS and its rationale between healthcare professional's community in order to increase the number of users ensuring full disease and country coverage. Broader dissemination among ERN-EuroBloodNet members have been performed through:

CPMS Operational Helpdesk section at ERN-EuroBloodNet website

ERN-EuroBloodNet CPMS section was created in EuroBloodNet website for users to retrieve support information on three different CPMS related sections:

ABOUT CPMS

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

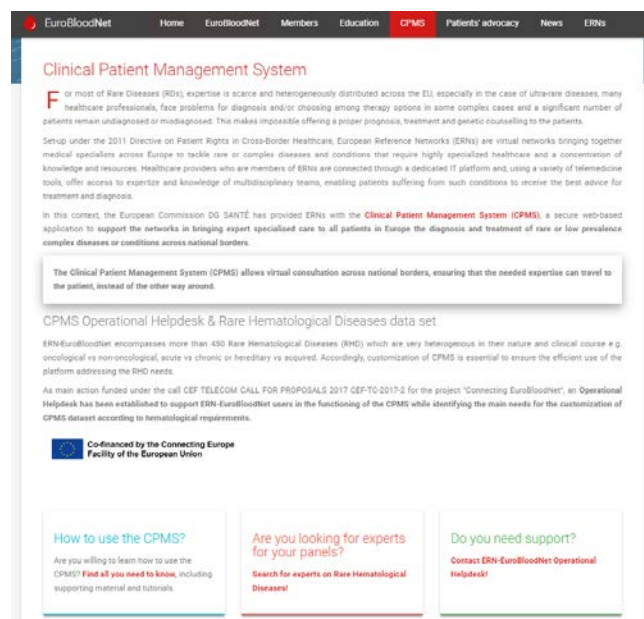
HOW TO USE THE CPMS

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

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

FIND EXPERTS FOR PANELS

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



Clinical Patient Management System

For most of Rare Diseases (RDs) expertise is scarce and heterogeneously distributed across the EU, especially in the case of ultra-rare diseases, many healthcare professionals face problems for diagnosis and/or choosing among therapy options in some complex cases and a significant number of patients remain undiagnosed or misdiagnosed. This makes impossible offering a proper prognosis, treatment and genetic counselling to the patients.

Setup under the 2011 Directive on Patient Rights in Cross-Border Healthcare, European Reference Networks (ERNs) are virtual networks bringing together medical specialists across Europe to tackle rare or complex diseases and conditions that require highly specialised healthcare and a concentration of knowledge and resources. Healthcare providers who are members of ERNs are connected through a dedicated IT platform and, using a variety of telemedicine tools, offer access to expertise and knowledge of multidisciplinary teams, enabling patients suffering from such conditions to receive the best advice for treatment and diagnosis.

In this context, the European Commission DG SANTE has provided ERNs with the **Clinical Patient Management System (CPMS)**, a secure web-based application to support the networks in bringing expert specialised care to all patients in Europe the diagnosis and treatment of rare or low prevalence complex diseases or conditions across national borders.

The Clinical Patient Management System (CPMS) allows virtual consultation across national borders, ensuring that the needed expertise can travel to the patient, instead of the other way around.

CPMS Operational Helpdesk & Rare Hematological Diseases data set

ERN-EuroBloodNet encompasses more than 450 Rare Hematological Diseases (RHD) which are very heterogeneous in their nature and clinical course e.g. oncological vs non-oncological, acute vs chronic or hereditary vs acquired. Accordingly, customization of CPMS is essential to ensure the efficient use of the platform addressing the RHD needs.

As main action funded under the call CEF TELECOM CALL FOR PROPOSALS 2017 CEF-TO-2017-2 for the project "Connecting EuroBloodNet", an Operational Helpdesk has been established to support ERN-EuroBloodNet users in the functioning of the CPMS while identifying the main needs for the customization of CPMS dataset according to hematological requirements.

Cofinanced by the Connecting Europe Facility of the European Union

How to use the CPMS?
Are you willing to learn how to use the CPMS? Find all you need to know, including supporting material and tutorials.

Are you looking for experts for your panels?
Search for experts on Rare Hematological Diseases!

Do you need support?
Contact ERN-EuroBloodNet Operational Helpdesk!

Informative bulletins

In order to support experts to creation their CPMS user, dedicated emails were sent to all ERN-EuroBloodNet members representatives and substitutes with the explanation of

- CPMS objectives
- Introduction on its use
- Importance of their feedback for the customization phase
- Brief steps on how to create an EU Login and to request access to the CPMS, including the CPMS documentation enclosed

In addition, a piece of news for disseminating the end of the project Connecting EuroBloodNet and starting of the continuation through Connecting EuroBloodNet II:

- [The project "Connecting EuroBloodNet" has recently finished with the establishment of the CPMS Operational Helpdesk and identification of CPMS customization](#)

Dedicated sessions at ERN-EuroBloodNet face to face meetings and European /National Congresses

Presentations in conferences/workshops/meetings where the objectives and main actions of the network were introduced to the audience. Some of them have been:

- ERN-EuroBloodNet Improvement in clinical patient management, Victoria Gutiérrez Valle, Catalan society of hematology and hemotherapy, 14 November 2018, Spain
- ERN-EuroBloodNet activities, María del Mar Mañú Pereira, ICKSH meeting, 14 March 2019, Korea
- ERN-EuroBloodNet activities, Fahed Ahssini, 5th EuroBloodNet Scientific and Strategic Board Meeting, 4 April 2019, Belgium
- Improving registries and clinical trials for rare diseases, María del Mar Mañú Pereira, Assessment of a European Expert Network on communicable diseases and other rare pathologies in the context of Mobility and Globalisation, 8 April 2019, Spain
- Telemedicine on the European platform, Fahed Ahssini, Belgian Hematology Society - Red Blood Cell Committee, 9 May 2019, Belgium
- ERN-EuroBloodNet activities, Fahed Ahssini, European Hematology Association annual congress, 13 June 2019, Netherlands
- Cross Border Health for rare cancer cases, Mariangela Pellegrini, Joint Action on Rare Cancers, 11 September 2019, Belgium
- Clinical Patient Management System, Béatrice Gulbis, ERN-EuroBloodNet 3rd Board of Network meeting, 13-14 November 2019, Spain

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. The following table 1 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):

COUNTRY	NUMBER OF REPRESENTED MEMBERS 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
UNITED KINGDOM	1	1
	37	61

Table 1. EuroBloodNet users of CPMS per country

Accordingly, 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

ERN-EuroBloodNet covers up to 450 RHD which present with prevalences ranging from 0,049% to 10⁻⁷%, meaning from 1 patient affected out of 2.032 individuals to 1 patient affected out of 101.600.000 individuals. Prevalences for the main groups of RHD have been reviewed and classified according to the following criteria:

- Ultra-rare RHD: prevalence equal or less than 1/50.000
- Prevalent RHD: prevalence equal or more than 1/10.000
- Rare RHD: more than 1/50.000 and less than 1/10.000

With this scenario, knowledge and expertise available is even more fragmented and scarce on those very rare diseases, hampering the participation of those experts on the open cases.

Accordingly, actions focused on very rare disease have been prioritized to allow the micromapping of the expertise available at the EU level, including:

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.

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 17th of February 2020, a total number of 22 panels have been created for RHDs since the launch of the CPMS, from which 7 are closed now with an outcome report produced and delivered to patient. Only one panel was archived and one aborted due to technical issues and urgency of the case. The ERN-EuroBloodNet has 69 registered users from which 41 are active users. There are 22 open panels on single patients' cases. The 19 of them passed the step of panel selection, 14 of them the data completion, 12 of them the assessment, 7 of them as already mentioned the outcome report and the same 7 were already signed off. Table 2 summarizes the report of activity.

Total EuroBloodNet Activity, 2020 Report
CPMS Activity

CPMS Activity									
	Registered Users		Active Users		Number Of Panels Newly Created		Number Of Panels		
	Total		Total		Total		Total		Total
EuroBloodNet		69		41		22			22

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	22	19	14	12	7	7	7	1	1

Table 2. Total CPMS activity for EuroBloodNet until 17.02.2020

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, table3 summarizes number of users by sub-thematic disease field:

SUB-THEMATIC AREAS (HP OF DIFFERENT SUBNETWORK MIGHT BE REGISTERED IN DIFFERENT CATEGORIES)	NUMBER OF ACTIVE USERS REGISTERED
AMYLOIDOSIS	12
CONGENITAL DYSERYTHROPOIETIC ANEMIA, BLACKFAN-DIAMOND ANEMIA, ACQUIRED BMF AND INHERITED BMF	22
HAEMOCHROMATOSIS AND OTHER RARE GENETIC DISORDERS OF IRON METABOLISM AND HEME SYNTHESIS	24
HAEMOGLOBINOPATHY	27
HAEMOPHILIA A, B, THE RARER CONGENITAL DEFICIENCIES OF OTHER COAGULATION FACTORS, VON WILLEBRAND DISEASE, INHERITED PLATELET DEFECTS	18
HEREDITARY ERYTHROENZYMOPATHIES AND RBC MEMBRANE DEFECTS	23
MYELODYSPLASTIC SYNDROME (MOS)	18
MYELOPROLIFERATIVE NEOPLASM (MPN)	15
RARE LYMPHOMAS	15

Table 3. Number of active users registered to subthematic areas.

1.2 ANALYSIS OF PANELS CREATED IN 2019

Attending to the number of cases entered in the CPMS between 1st of January 2019 and 31st December 2019, the highest number of panels entered have been for the advice on both the diagnosis and treatment of hereditary erythroenzymopathies and Red Blood Cell (RBC) membrane defects, which represent, which represent 4 of the 12 panels opened. Another one was requested on Myelodysplastic syndrome (MOS).

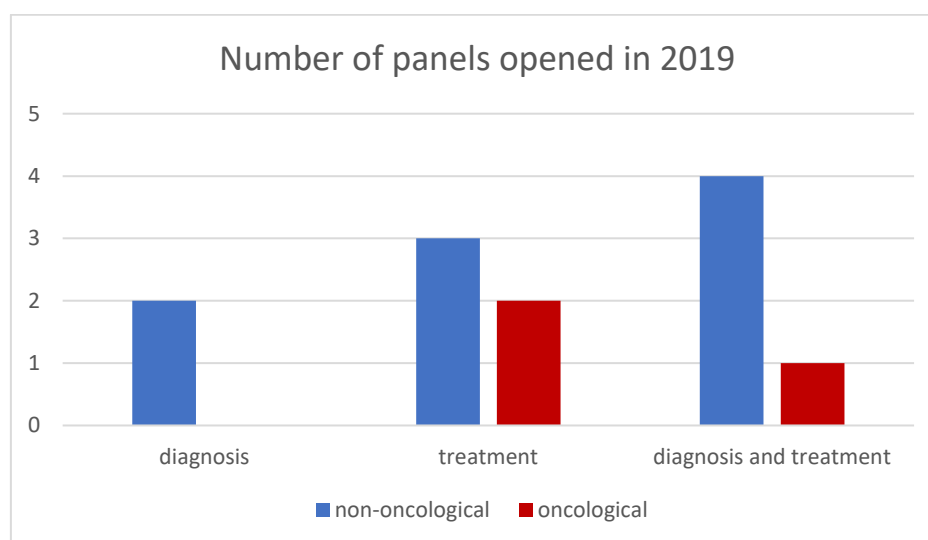
The number of requests for advice on treatment was distributed among Congenital dyserythropoietic anemia, Blackfan-Diamond anemia, Acquired Bone Marrow Failures (BMF) and Inherited BMF (2), Rare lymphomas (1), Myeloproliferative neoplasm (1) and Haemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis (1).

The advice on diagnosis was requested for one case on Hereditary erythroenzymopathies and RBC membrane defects and one case on Haemophilia A, B, the rarer congenital deficiencies of other coagulation factors, Von Willebrand disease, inherited platelet defects. Table 4 summarizes the character of panels created between 1st of January 2019 until 31st December 2019.

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

Table 4. Panels by thematic area and advice required

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 non-oncological disorders an important need is identified for the diagnosis and treatment advice representing 4 of the 9 cases entered, then the need for treatment representing 3 cases, and the need for diagnosis with 2 requests. While, for oncological diseases were 2 requests for the treatment advice, one advice on diagnosis and treatment, but in contrast to non-oncological diseases, no requests for the diagnosis. Only 3 cases from 12 were correlated to oncological RHD. Graph 1 summarizes the requests for diagnosis and treatment for oncological and non-oncological diseases between 1st of January 2019 and 31st December 2019.



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

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 THREE YEARS

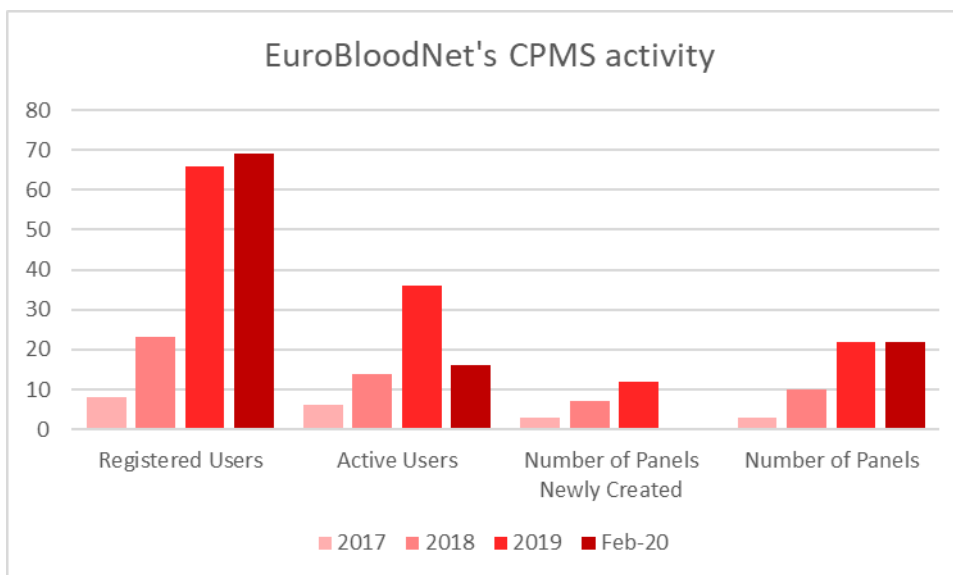
The yearly report shows the increase of ERN-EuroBloodNet CPMS activity in comparison to previous two years. The registered number of users increased almost three times in comparison to 2018, the number of active users increased more than twice, the number of newly created panels increased by 5, giving the total number of 22 panels created until the 17th of February 2020. In 2019 a number of 12 panels were opened, 10 passed the step of panel selection, 8 of panel completion, 7 of assessment, 5 delivered the outcome report and were signed off, 6 were closed and only one was archived. Table 6 presents the yearly reports of ERN-EuroBloodNet CPMS activity and Graphs 2 and 3 summarizes its outcomes.

Total EuroBloodNet Activity, Yearly Report CPMS Activity

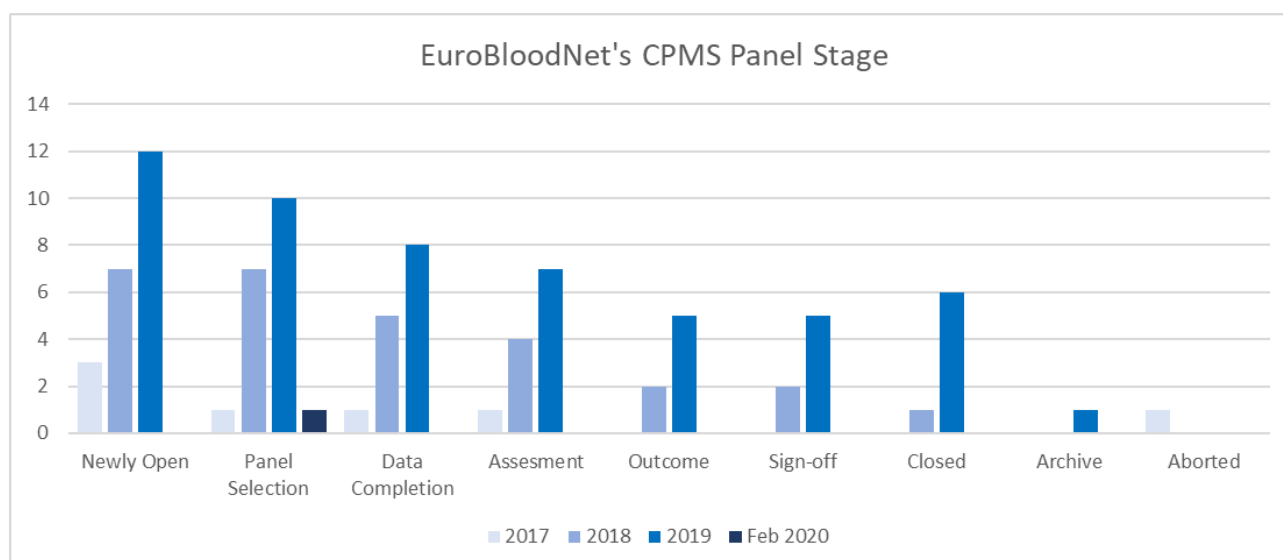
CPMS Activity																			
	Registered Users				Active Users				Number Of Panels Newly Created				Number Of Panels						
	2017	2018	2019	2020	2017	2018	2019	2020	2017	2018	2019	2020	2017	2018	2019	2020			
EuroBloodNet	8	23	66	69	6	14	36	16	3	7	12	0	3	10	22	22			

CPMS Panel Stage																																			
	Open		Panel Selection				Data Completion				Assessment				Outcome				Sign-Off				Closed			Archive			Aborted						
	2017	2018	2019	2020	2017	2018	2019	2020	2017	2018	2019	2020	2017	2018	2019	2020	2017	2018	2019	2020	2017	2018	2019	2020	2018	2019	2020	2018	2019	2020	2017	2018	2019	2020	
EuroBloodNet	3	7	12	0	1	7	10	1	1	5	8	0	1	4	7	0	0	0	2	5	0	0	2	5	0	1	6	0	0	1	0	1	0	0	0

Table 6. Yearly CPMS activity for ERN-EuroBloodNet



Graph 2. Yearly report on EuroBloodNet's CPMS activity.



Graph 3. Yearly report on EuroBloodNet's CPMS Panel Stage.

2.2 INCREASE IN COUNTRY COVERAGE

ERN-EuroBloodNet has incorporated the following affiliated partners:

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

Official collaborations are established based on collaborations agreements, which include an item regarding a minimum number of patients introduced in the CPMS. This number is estimated by each center based on the complex cases that may have per year.

At the time of this report, Associated National Centers have already access to CPMS.

In addition, a reference person has been identified to act as a bridge among ERN-EuroBloodNet and Eastern countries, which are less represented in the networks and the use of CPMS may be highly required. This action will be promoted in the coming actions of implementation.

2.3 INCREASE IN DISEASE COVERAGE

Two very rare disease groups have been already identified for the establishment of Expert Virtual Boards participating actively in the sharing of complex cases and participating in the open panels. The two Boards will be implemented in the context of Connecting EuroBloodNet II, including:

1. Cutaneous Lymphoma disorders
2. Hemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis

5. CONCLUSIONS AND NEXT STEPS

Wide implementation of the CPMS is in itself a challenge, considering that medical community has to make a U-turn from an “easy” email exchanging with colleagues to a more “complex” and structured system. At this moment the CPMS is not well known among the experts of ERN-EuroBloodNet even that the promotion has already started.

CPMS brings excellent solutions for the exchange of RD complex cases, although as a new platform requires

- 1) Higher promotion by ERN community,
- 2) Strong collaboration between users and CPMS support team how to improve its technical features.

Promotion of the CPMS within and outside ERN-EuroBloodNet is paramount to ensure its efficient use and wider outreach among the rare hematological diseases health professionals requiring advice for a complex case or willing to provide advice on complex cases of their expertise. Accordingly, the definition of a strategy that allow the increase of the number of panels, country and disease coverage created in the platform is essential to guarantee the success of the platform in the context of rare hematological diseases.

In close collaboration with Connecting EuroBloodNet I and II grants, dedicated efforts have been focused on increasing the awareness on the CPMS and its rationale between healthcare professional’s community ensuring full disease and country coverage, including:

- CPMS Operational Helpdesk section at ERN-EuroBloodNet website, including guiding material and tutorial videos
- Informative bulletins on the platform, as dedicated emails and pieces of news
- Dedicated sessions at ERN-EuroBloodNet face to face meetings and European/National Congresses
- Organization of CPMS working days to help with registration of new patient cases
- Presentation of the platform to new Affiliated members
- Stress the possibility of inviting to CPMS non-member experts or experts from other ERNs

In addition, based on the analysis of the CPMS panels stage and yearly activity, it is observed that most of panels remain stuck at the initial phases of the flowchart. The need of decreasing the time spent until the achievement of the outcome has been identified as an indicator that needs to be decreased for the facilitation of the provision of advice on duly time and thus, for the final provision of best care to the patients.

Accordingly, for next steps it is expected:

- a) To continue with the promotion of the CPMS following the strategy identified and including the new communication channels established with RHD stakeholders, ie. ERN-EuroBloodNet Facebook and LinkedIn profiles
- b) To consolidate the role of ERN-EuroBloodNet CPMS Help Desk as the main contact point to support of users on the creation of panels and provision of advice, while ensuring a smooth transition on the workflow stages by
 - a. Technical assistance via email or webex to CPMS users on every step of the panel
 - b. Observe and coordinate panels, contact physicians and remind/motivate them for actions necessary to make a progress on the panel they are involved in
- c) To develop and disseminate informative materials for HP and patients on how they can benefit from CPMS

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

- a) Implementation of the customization data set according to ERN-EuroBloodNet needs identified.
- b) Promote the use of the platform for very rare diseases by the establishment of virtual boards of experts committed to the consultation of patients' cases on regular basis. At this stage two groups of very rare diseases have been identified as target of this action and experts boards are currently being identified, including:
 1. Cutaneous Lymphoma disorders
 2. Hemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis



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



www.eurobloodnet.eu

Co-funded by the European Union

