

ERN-EUROBLOODNET

EUROPEAN REFERENCE NETWORK ON RARE HEMATOLOGICAL DISEASES

2.2.1 CORE : THE ERN HAS IMPLEMENTED A PROCESS FOR OFFERING ADVICE FOR COMPLEX PATIENT CASES PROVIDED BY MULTIDISCIPLINARY HEALTHCARE TEAMS

ANNEX III

**ANALYSIS OF STRATEGIES AND RESULTS OF THE MONITORING INDICATORS
2.2, 3.1, AND 3.2 (CPMS RELATED INDICATORS)**

INTRODUCTION

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 (CPMS), 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, ERN-EuroBloodNet has promoted the use the CPMS by implementing strategies to:

- Enhance experts's awareness and training in the CPMS through the Implementation of a helpdesk
- Promote the development of expert virtual boards for consulting very rare and complex cases In rare hematological diseases;

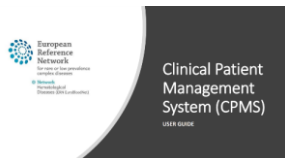
Results of this strategy are reflected by the monitoring Indicators 2.2, 3.1; 3.2.

TRAINING AND AWARENESS OF EXPERTS:

The ERN-EuroBloodNet Operational helpdesk was established to support the communication and understanding between the users in Healthcare providers (HCPs) and the Core services IT engineers. Besides this, the CPMS Helpdesk was in charge of registration of CPMS users and technical support for the ERN members, non-members and affiliated partners who wanted to contribute to the consultations in CPMS. This was 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

Accordingly, a dedicated section was created on the ERN-EuroBloodNet Website section on ["How to use the CPMS"](#). It Includes the following training material that were produced during the period:



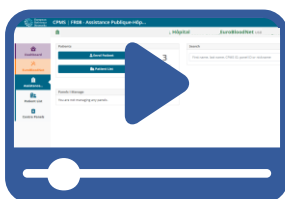
3 comprehensive guides to present and explain the use of the platform:

- general overview of the CPMS in a brief user guide
- Registration Guide
- Enrol a patient Guide



4 One-page guides to get quickly familiar with the tool:

- One-page CPMS 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



6 Short Video Tutorials on:

- "How to create and activate your account"
- "How to create a panel"
- "How to invite an expert to your panel"
- "How to schedule a meeting"
- "How to upload images to your panel"
- "How to record your contribution"

In parallel, the ERN-Helpdesk provided assistance to experts wishing to join the platform by email and by online- training workshops. Such workshops included all the necessary steps in order to register and train a new user on all the practical aspects of CPMS:

- a) establishment of EU Login,
- b) request for authorization in SaaS,
- c) first login to CPMS,
- d) defining the profile of expertise in CPMS's account,
- e) simulation on patient enrollment, panel opening, and joining the panel in the CPMS training Environment.

To promote awareness on the use of the platform, online bulletins of Information disseminated by the ERN-EuroBloodNet newsletter and social medias were created. They included information on initiatives correlated with EuroBloodNet's CPMS such the formation of Virtual Boards and publication of the updated versions of guides.

Dedicated sessions at ERN-euroBloodNet Meetings such as the Board of the Network (BoN), Scientific and Strategic Board Meetings (SSB), and Progress Meetings, contributes to sharing of experience and promotion of the tool among ERN-euroBloodNet Members.

A total of **19** sessions on the CPMS were held during the first 5 years of implementation:

2017:

- Kick-Off Meeting & 1st SSB Meeting, Vilnius, 9-10th March 2017: "*First steps in each TFA* "
- 1st BoN Meeting, Paris, 10th November 2017: "*Telemedicine*"
- 2nd SSB Meeting : Brussels, 6th September 2017, "*Telemedicine*"

2018:

- 3rd SSB Meeting, Brussels, 5th April 2018: "*TFA on Telemedicine*"
- 4th SSB Meeting, Brussels, 27th September 2018:
 - o "*CPMS : State of the art: users, function, customization* "
 - o "*Connecting ERN-EuroBloodNet: CEF Telecom Grant - starting 1st October*"
- 2nd BoN Meeting, Paris 8th of November 2018: "*Clinical Patient Management System (CPMS)*"
- Catalan society of hematology and hemotherapy, Spain, 14th November 2018 : "*ERN-EuroBloodNet Improvement in clinical patient management*"

2019:

- ICKSH meeting, 14 March 2019, Korea :"*ERN-EuroBloodNet activities*"
- 5th EuroBloodNet SSB Meeting, Belgium, 4th April 2019: "*ERN-EuroBloodNet activities*"
- Assessment of a European Expert Network on communicable diseases and other rare pathologies in the context of Mobility and Globalisation, Spain, 8th April 2019: "*Improving registries and clinical trials for rare diseases*"
- Belgian Hematology Society - Red Blood Cell Committee, 9 May 2019, Belgium: "*Telemedicine on the European platform*"
- European Hematology Association annual congress, 13 June 2019, Netherlands: "*ERN-EuroBloodNet activities*"
- Joint Action on Rare Cancers, 11 September 2019, Belgium: "*Cross Border Health for rare cancer cases*"
- ERN-EuroBloodNet 3rd BoN meeting, 13-14 November 2019, Spain: "*Clinical Patient Management System*"

2020:

- 4th ERN-EuroBloodNet BoN Meeting, 22nd of October 2020: "*CPMS Clinical Patient Management System*"
- 4th EuroBloodNet BoN Meeting, 22nd of October 2020: "*CPMS Cutaneous Lymphoma*"
- Meeting with Cutaneous Lymphoma Experts, 7th of April 2020 : "*Virtual Board in CPMS for Cutaneous Lymphoma*"

2021:

- ERN-EuroBloodNet Webinar for Patients organizations, 26th April 2021, Online: "How to connect patients in Europe to Cutaneous Lymphoma experts via the ERN"
- ERN-EuroBloodNet Progress Meeting, 21st May 2021, Online:
 - o "*General overview of the Clinical Patient Management System*"
 - o "*The Experience of Cutaneous Lymphoma Virtual Boards*"
- ERN-EuroBloodNet 2nd Progress Meeting, 28th October 2021, Online: "*Focus on EuroBloodNet actions for Cutaneous Lymphoma*",

VIRTUAL BOARDS

The CPMS Virtual Board model has been developed based on a pilot for Cutaneous Lymphoma (CL) as an ultra-rare cancer with very concrete expert needs with the aim to a) train experts in the use of the CPMS, b) establish regular CPMS video meetings, and c) develop logistics for open consultation to non-member requests and timely outcome delivered to patient.

The CPMS Virtual Board on CL was defined with the selection of European Organisation for Research and Treatment of Cancer Cutaneous Lymphoma Working Group (EORTC CLWG) members based on number of patients per center and access to advanced medical tools. As a result, Virtual Board was configured with 18 multidisciplinary experts including **3** hematologists, **1** hematopathologist, **11** dermatologists, **7** dermatopathologists, **3** dermatooncologists, **3** oncologists

From them, 8 were specialists from ERN-EuroBloodNet's Member Healthcare Centers, 2 from ERN-EuroBloodNet's Affiliated Partners and 8 from Supporting Partners. Experts and affiliation of the Virtual Board on CL is available at [ERN-EuroBloodNet website](#).

A total of **12** dedicated online workshops have been provided by the ERN-EuroBloodNet CPMS helpdesk to the Virtual Board on CL resulting in 15 Experts registered and trained in CPMS and 2 residents/assistants managing patients' enrolment at HCPs. A specific panel consultation form had been developed by the group to improve the panel management and the inclusion of all relevant aspects of the patient profiles (diagnosis, social and psychological aspects etc...).

A total of **14** Meetings were held by the CL Virtual Board (among which, 7 in the CPMS platform). **9** cases have been enrolled in the period, with 8 outcome reports generated.

Based on this successful experience, the Virtual Board model has been developed to another disease area, in rare Haemolytic anaemias.

CUSTOMIZATION OF THE CPMS

Given the complexity and technical issues faced by ERN-EuroBloodNet experts, actions have been undertaken to customize the CPMS and to adapt the platform to the specific needs and characteristics of Rare Haematological Diseases (RHD).

A specific data set has been developed as a result from the gathering of feedback and input from all the CPMS actions performed from January 2019 to September 2019. After compiling all the feedback from experts, the variables for customization were organized in the most logical and comprehensive way while avoiding any redundant data in the datasets. Requests and recommendations are available in the Annex II of Measurable element 2.2.1 (ERN-EuroBloodNet CPMS needs). This outcome gathers the key parameters common to all the RHD for ensuring the adequate gathering of data for a) laboratory findings and b) follow up of the patients based on the RHD transversal needs, while sets the basis for a disease-specific customization. However, this data set is still pending for implementation from the European Commission.

On the other hand, Virtual Boards have developed different panel management strategies and tools in order to ensure the faster delivery of advice and outcomes, such as:

- Enrolling their contributions directly within the chat box in the CPMS (Virtual Board on HA)
- Or meeting regularly in video meeting tool on the CPMS (Virtual Board on CL)

A consultation form has been developed and used to complete the clinical patient data in more efficient and structured way. All these "best practices" reflect how experts from the network have tried to develop strategies to adapt the platform to their needs and to overcome the technical limitations faced within the CPMS. These strategies have been presented during ERN-EuroBloodNet meetings (for example, with a dedicated slot in the Progress Meeting of May 2022 to facilitate the entry of cases in the CPMS).

Finally, based on the experience of its members and affiliated partners, the ERN-EuroBloodNet coordination has taken part to the discussion on the needs for improvement of the current platform, and the development of the new CPMS version with the European Commission and the IT team managing the tool. The CPMS Helpdesk has been regularly alerting the European Commission's IT team about technical or complexity issues faced in the platform. Discussion have

also started in 2021 regarding the need of a new CPMS version and the network has taken part actively to the discussion in order to reflect the specific demands of its members.

RESULTS

According to the ERN Status report on the CPMS provided by the European Commission, the following results were obtained:

Between 2017 and 2021, a total of 43 patients were enrolled in the platform (among which 7 were enrolled by Guests profiles, 8 by ERN-EuroBloodNet full members, 4, by ERN-EuroBloodNet affiliated partners): This number reflects that the ERN-EuroBloodNet strategy managed to reach not only ERN-EuroBloodNet members, but also affiliated partner and centres outside the network where the expertise might be lacking: See table 1 and Figure 1.

	2017	2018	2019	2020	2021	2017-2021
Number of new patients referred to Health Care Providers with a diagnosis of diseases/ conditions that fall within the scope of the ERN	8104	9069	16927	10199	11669	55968
Number of patients enrolled into CPMS	4	7	13	12	7	43
Number of patients enrolled into CPMS by Guests				7	0	7
Number of patients enrolled into CPMS by Full members				5	3	8
Number of patients enrolled into CPMS by Affiliated Partners				0	4	4

Table 1. Results of monitoring indicators 2.1 and 2.2

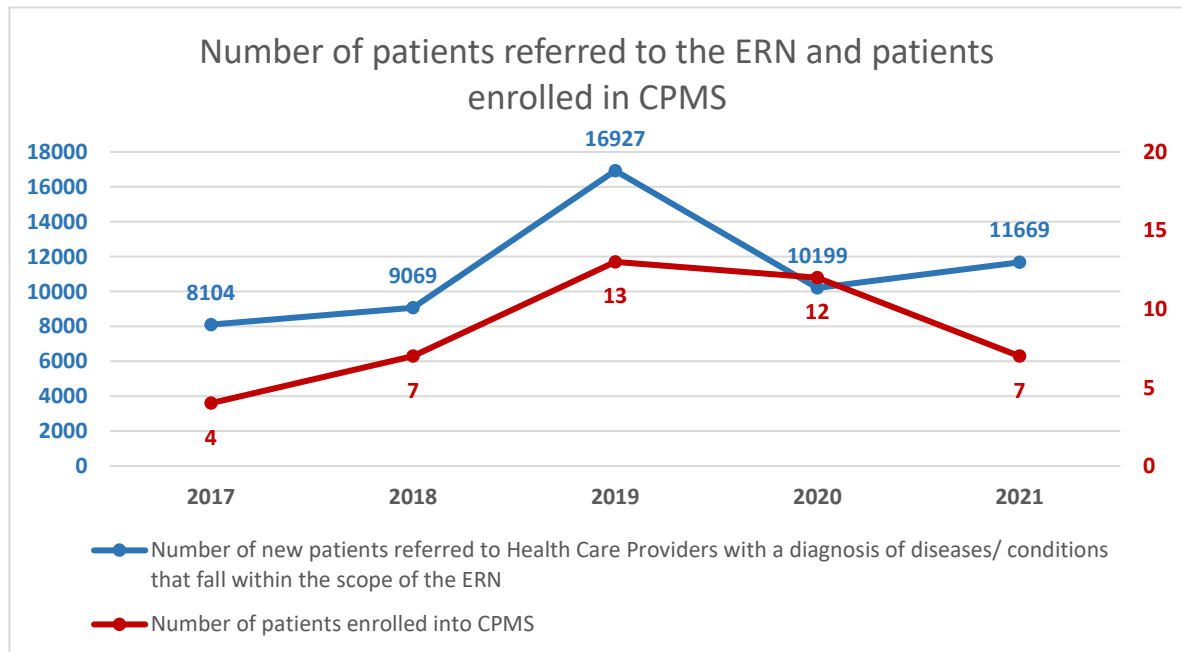


Fig. 1 Results of Indicators 2.1 and 2.2

Regarding the panels creation and management in the platform: 42 panels have been created between 2017 and 2021 for Rare haematological diseases, from which 21 are closed with outcome report produced (See table 2 and Figure 2). 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.

3. Patients enrolled in CPMS and panel case reviews created	2017	2018	2019	2020	2021	2017-2021
Number of patients enrolled into CPMS	4	7	13	12	7	43
Urgent Panels						
Total number of panel case reviews for review which led to an outcome report – urgent panels	0	1	1	3	0	5
Guests - Total number of panel case reviews for review which led to an outcome report				7	0	7
Full Members - Number of panel case reviews for review which led to an outcome report – urgent panels				1	0	1
Affiliated Partners - Number of panel case reviews for review which led to an outcome report – urgent panels				0	0	0

Table 2. Results of Indicators 2.1 and 3.1 (Urgent panels)

3. Patients enrolled in CPMS and panel case reviews created	2017	2018	2019	2020	2021	2017-2021
Non-urgent Panels						
Total number of panel case reviews for review which led to an outcome report – non-urgent panels	3	6	10	9	1	29
Guests - Number of panel case reviews for review which led to an outcome report – non-urgent panels				5	0	5
Full Members - Number of panel case reviews for review which led to an outcome report – non-urgent panels				4	1	5
Affiliated Partners - Number of panel case reviews for review which led to an outcome report – non-urgent panels				0	0	0

Table 2. Results of Indicators 2.2 and 3.1 (non-urgent panels)

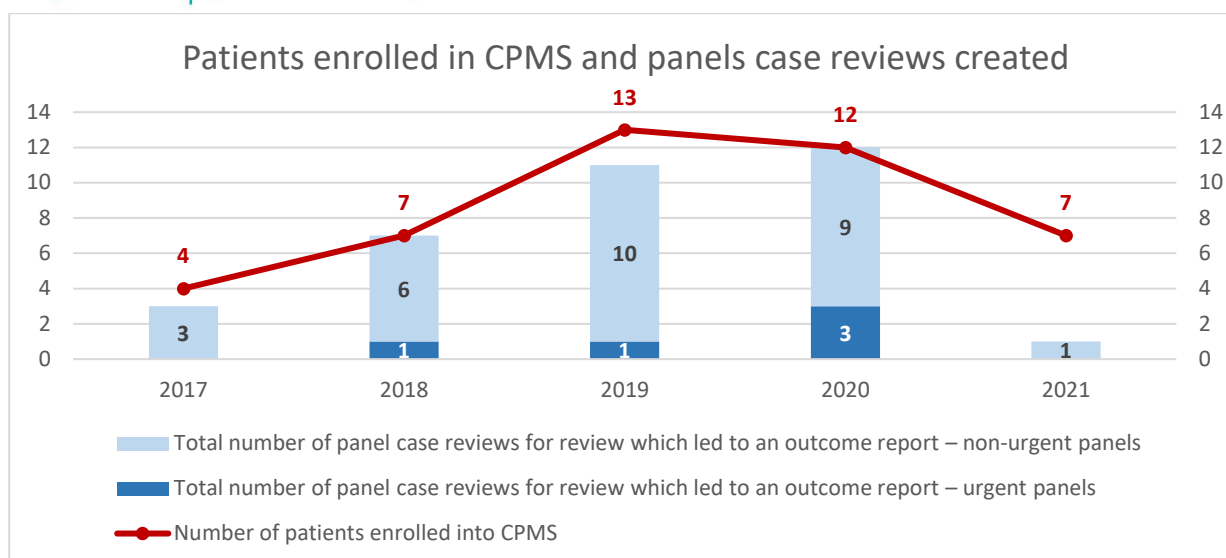


Fig. 2. Results of the monitoring indicators 2.2 and 3.1

4. Time taken to provide multidisciplinary advice:	2017	2018	2019	2020	2021
Median days between referral to ERN and multidisciplinary advice – urgent panels				29	0
Guests - Median days between referral to ERN and multidisciplinary advice – urgent panels				34	0
Full Members - Median days between referral to ERN and multidisciplinary advice – urgent panels				20	0
Affiliated Partners - Median days between referral to ERN and multidisciplinary advice – urgent panels				0	0
Weighted average of median days for Guests, Full Members and Affiliated Partners - urgent panels				29,3	0

Table. 3: Results of the monitoring indicator 3.2 (urgent panels)

4. Time taken to provide multidisciplinary advice:	2017	2018	2019	2020	2021
Median days between referral to ERN and multidisciplinary advice – non-urgent panels	0			74	147
Guests - Median days between referral to ERN and multidisciplinary advice – non-urgent panels				33	0
Full Members - Median days between referral to ERN and multidisciplinary advice – non-urgent panels				125	147
Affiliated Partners - Median days between referral to ERN and multidisciplinary advice – non-urgent panels				0	0
Weighted average of median days for Guests, Full Members and Affiliated Partners - non-urgent panels				73,8	147

Table. 3: Results of the monitoring indicator 3.2 (non-urgent panels)

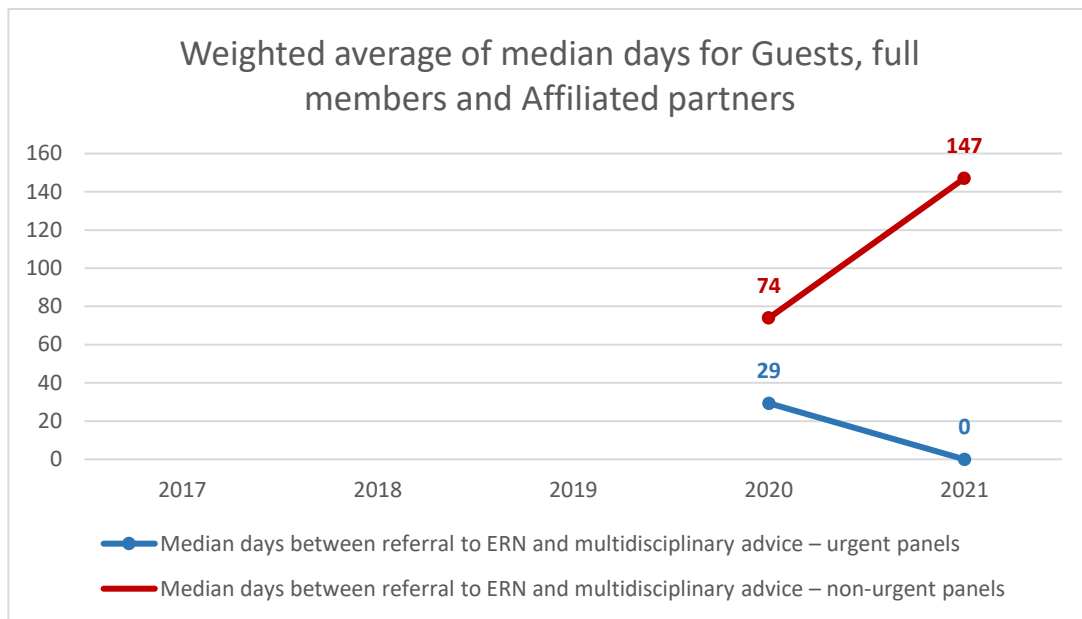


Fig. 3: Results of the monitoring indicator 3.2

Moreover, by the end of 2021, 80 active Users were registered in the platform (See figure 4) . The growth of number of newly registered user indicates that ERN-EuroBloodNet's actions managed to activate already registered users by providing them technical support and guiding them through the platform. In terms of coverage, the report reveals that the panels created were opened from 9 different countries covered by the network. The figure 5 highlights some remaining gaps in the disease coverage especially in the central-Balkan Europe. Finally, ERN-EuroBloodNet CPMS panels were equally spread among oncological diseases (20 panels) and non-oncological diseases (22 panels). Within these thematic areas, the diseases more reported in the CPMS were the ones covered by the two Virtual Boards established by the network: Cutaneous lymphoma, and Red blood cells membrane defects. These numbers (see figure 6) reflect the positive impact of the virtual board model in covering ultra-rare diseases requiring specific collaboration mechanisms for complex case consultation.

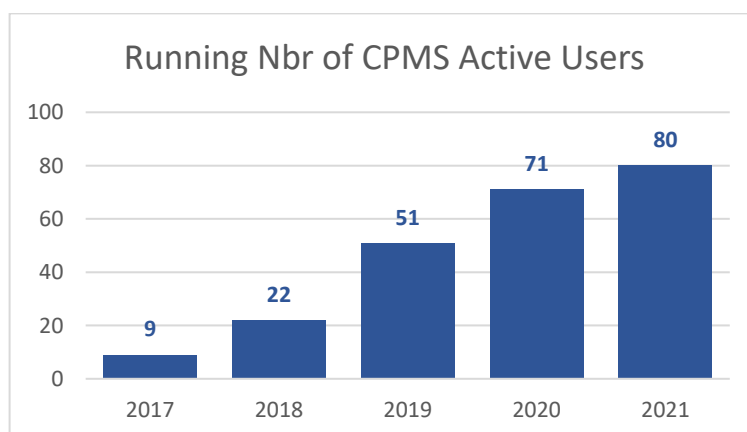


Fig. 4 : Running number of CPMS active users between 2017 and 2021

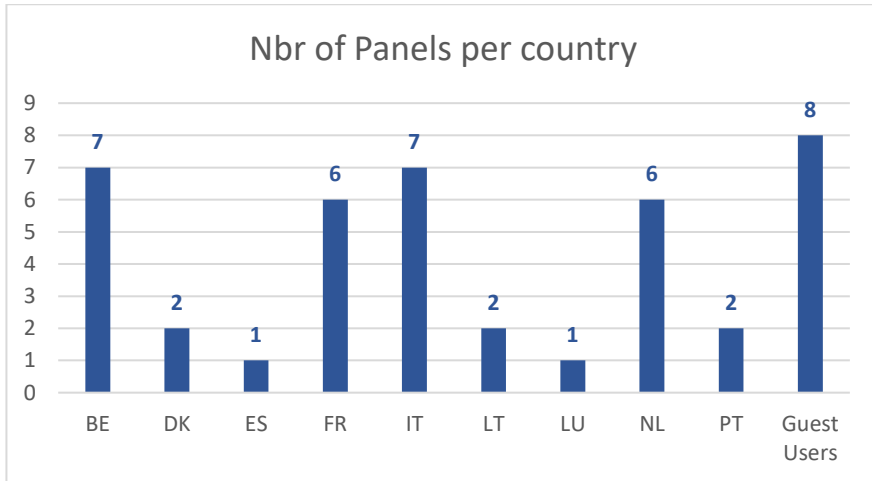


Fig. 5: Number of panels created in the CPMS per country

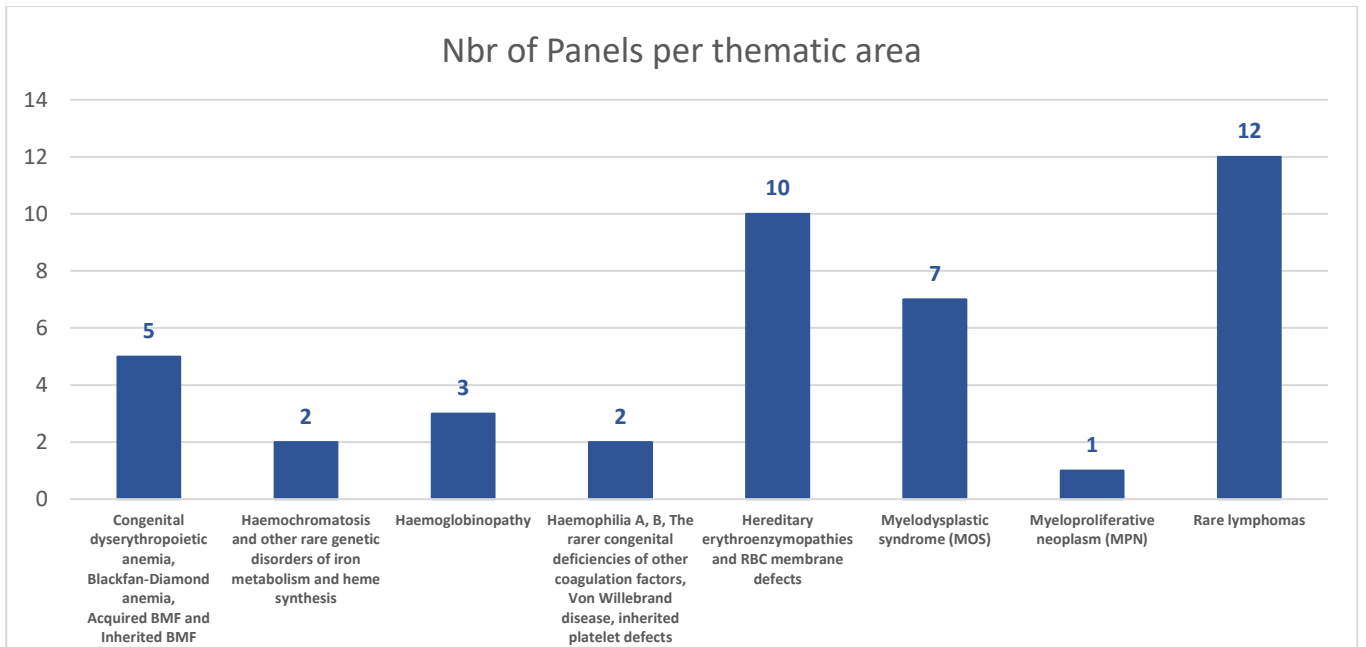


Fig. 6: Number of Panels per thematic area.

CONCLUSION

The CPMS can play a crucial role in covering important gaps in the field of ultra-rare diseases resulting from their low prevalence. ERN- EuroBloodNet has Implemented several strategies and mechanisms to boost Its use, which brought 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. 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 ERN-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

Moreover, ERN-EuroBloodNet will continue to promote 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.

The implementation of pilot schemes to provide economical support for HCPs opening the case consultations in the CPMS, and the development of a new CPMS version, more easy to use, will foster the achievement of these objectives.



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



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As of the 1st of April 2021 the Consumers, Health, Agriculture and Food Executive Agency (CHAFEA) ceased to exist. The portfolio of actions managed by CHAFEA under the 3rd HP was transferred to the Health and Digital Executive Agency (HaDEA).