

ERN-EuroBloodNet Progress Meeting Outcomes

28th October, Online



Coordination team:

Pierre Fenaux – Coordinator & Chair of oncological hub

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On the last 28th of October, almost 140 participants attended the 2nd edition of the online [ERN-EuroBloodNet](#) Progress meeting. As a novelty, different polls were conducted during the meeting about the actions targeted in the [ERN-EuroBloodNet](#).

Four main topics divided the meeting:

1. Introduction: A new framework for the ERN-EuroBloodNet
2. Session I: Diseases on Focus
3. Session II: Guidelines & Continual Medical Education
4. Session III: Innovation & Research

1. Introduction: A new framework for the ERN-EuroBloodNet

The meeting was initiated with a welcome message by the [ERN-EuroBloodNet](#) co-coordinators [P Fenaux](#) ([Assistance Publique – Hôpitaux de Paris, Hôpital Saint-Louis](#)) and [B Gulbis](#) ([CUB-Hôpital Erasme](#)). [J Valverde](#) ([DG-SANTE, European Commission](#)), the new Policy Officer at [DG-SANTE](#), provided the second talk: “**ERN’s challenges and opportunities**”. Finally, [V Gutiérrez Valle](#) ([ERN- IT&Dissemination manager, Hospital Universitari Vall d'Hebron](#)) presented “**ERN-EuroBloodNet’s 5 years implementation**”.

Main Points highlighted during the discussion:

- ERN’s challenges and opportunities:
 - ✓ The idea is that the evaluation manual for existing Members will be provided by AMEQUIS in the first quarter of 2022.
 - ✓ A new call for new Members is not planned for 2022.
 - ✓ The European Commission (EC) is dealing with several points concerning Members of ERNs; such as the termination of some Members due to the lack of participation or expertise; the unification of the team of experts between centres; the movement of the expertise between centres.
 - ✓ The EC cannot interfere with the strategy that is being implemented at the national level for rare diseases.
- The support of the Healthcare Providers (HCP) is not always provided to the experts involved in the ERNs. As important stakeholders, they must understand the importance of their support to ERNs. To this aim, the EC organized a meeting to stimulate their involvement in the maintenance and development of ERN’s actions.
- “ERN-EuroBloodNet’s 5 years implementation”:

The reimbursement on Cross-border health is an aspect that is not under the scope of the ERNs. The role of the [ERN-EuroBloodNet](#) in this project is only at the coordination level.

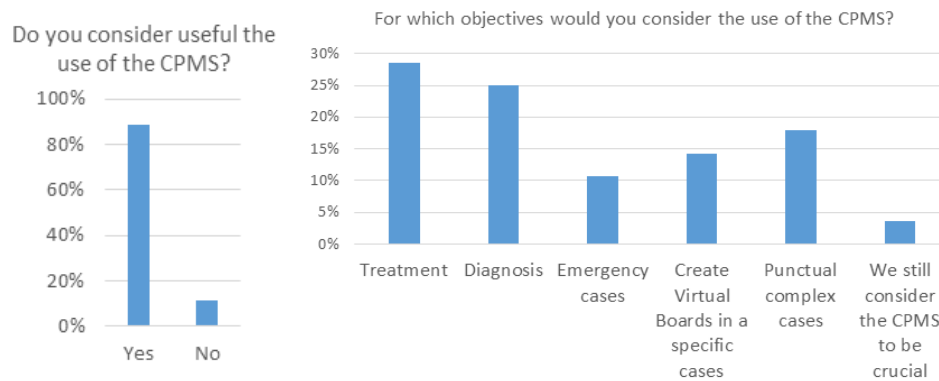
2. Session I: Diseases on Focus

This section of the meeting focused on several diseases targeted in ERN-EuroBloodNet. The first presentation about the ongoing projects on **Cutaneous Lymphoma (CL)** was provided by [M Bagot](#) ([Assistance Publique – Hôpitaux de Paris, Hôpital Saint-Louis](#)) and N Bolaños ([Lymphoma Coalition Europe](#)). The second lecture focused on Cross Border Health and Patients' activities for **Sickle Cell Disease (SCD)**. In this occasion the expert [R Colombatti](#) ([AO Padua](#)) and the patient advocate L Brunetta ([ERN-EuroBloodNet ePAG](#), [Thalassaemia International Federation \(TIF\)](#)) were the speakers of the talk. The following presentation was related to **Aplastic Anemia and Paroxysmal Nocturnal Hemoglobinuria (AA and PNH)**. The different actions approaching this disease were presented by [R Peffault De Latour](#) ([Assistance Publique – Hôpitaux de Paris, Hôpital Saint-Louis](#)) and [M Pellegrini](#) ([ERN-EuroBloodNet Educational & Patients Program Manager](#), [Assistance Publique – Hôpitaux de Paris, Hôpital Saint-Louis](#)).

Main Points highlighted during the discussion:

Questions abroad:

- ✓ In the future, on-side and virtual meetings will be organized by [ERN-EuroBloodNet](#).
 - ✓ Based on our experience, we have observed that online tools enable major audiences, including non-European countries, such as Malaysia, New Zealand, Australia. Nevertheless, the model of the workshop cannot be adjusted to the virtual tool. For this reason, on the side and virtual educational sessions must be considered for future projects.
 - ✓ The material is always available on [ERN-EuroBloodNet](#) website after the meetings.
 - ✓ An official letter for the implementation of a systematic screening for the detection of carriers will be important for the prevention and diagnosis of rare severe Haemoglobinopathies.
 - ✓ Any expert willing to perform a Mapping of Expertise can contact us.
- “Focus on Cutaneous Lymphoma”:
 - ✓ A better implementation of the TCD guidelines is necessary.
 - ✓ CPMS is a tool that can be use by Health professionals from all EU. It is considered useful for the 89% of the health professionals answering the poll. They consider most useful its application for the discussion of treatments and Diagnosis.



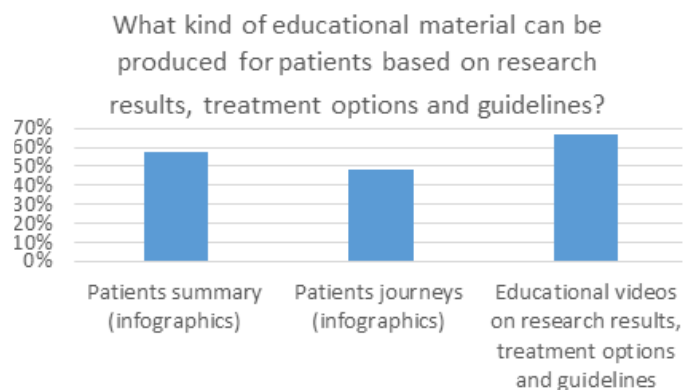
- ✓ The complexity of the CPMS is one of the most problematic points for the engagement of experts. The EC is working in the improvement of the platform.
- “Cross Border Health and Patients’ activities for Sickle Cell Disease”:
 - ✓ There is no official recognized action for the systematic screening for refugees. Due to the availability of rapid tests could be considered as an interesting activity to be performed by [ERN-EuroBloodNet](#).
 - ✓ There are no common steps to be undertaken for cross-border health focused on Bone Marrow Transplant (BMT) for SCD patients. Agreements have to be detailed by the centers involved (sender and receptor) due to the broad legislation on cross-border healthcare.
 - ✓ A list of Members providing BMT will be available for Members.
 - ✓ Gene therapy for SCD cannot be provided in Europe. To change this, ERN-EuroBloodNet and the Gene Therapy Group will present an official petition to the European level.
- 92% of the healthcare providers consider necessary a Mapping of Experts and Specialized Procedures. Among those, 45% are willing to coordinate one.
- “Focus on Aplastic Anemia and Paroxysmal Nocturnal Hemoglobinuria”:
 - ✓ The Preceptorships have been beneficial for both parties. It has allowed the creation of a scientific network on Aplastic Anemia and Paroxysmal Nocturnal Hemoglobinuria.

3. Session II: Guidelines & Continual Medical Education

The second session of the meeting was composed of three talks. The first one, “**Guidelines and other Clinical Decision Support Tools**”, was presented by [L Malcovati](#) (ERN-EuroBloodNet chair, [Foundation IRCCS Polyclinic San Matteo, Pavia](#)) and [P Bianchi](#) ([Foundation IRCCS Ca’Granda Ospedale Maggiore Policlinico, Milan](#)). The second talk, titled “**ERN-EuroBloodNet e-Learning Platform and Webinars**”, was provided by [P Aguilar-Martínez](#) ([CHU Montpellier](#)) together with [M Pellegrini](#) (ERN-EuroBloodNet Educational & Patients Program Manager, [Assistance Publique – Hôpitaux de Paris, Hôpital Saint-Louis](#)). Finally, a review of the “**Publications endorsed by ERN-EuroBloodNet**” was imparted by [N Roy](#) ([European Hematology Association \(EHA\) Guidelines Committee Chair, Oxford University Hospitals NHS Foundation Trust](#)) and [P Kountouris](#) ([Cyprus Institute of Neurology and Genetics \(CING\), Archbishop Makarios III Hospital](#)).

Main Points highlighted during the discussion:

- “Guidelines and other Clinical Decision Support Tools”:
- ✓ Initially, a list of 10 potential topics was selected from the different options provided by the Members. The 2 most important were approached:
 - oncological: Leukaemia and Burkitt Lymphoma
 - non-oncological disorders: Long term complications of Haemoglobinopathies.
 The development of the two guidelines is supported by the EC appointed consortium.
- ✓ After the identification of the topics a process for the appointment of the expert panel will start. Expertise from [ERN-EuroBloodNet](#) and external will be considered.
- ✓ Additional possibilities will be approached for the identification of other Guidelines to develop or consensus statements:
 - Developed as an [ERN-EuroBloodNet](#) initiative
 - Appropriate process of up rise and adoption endorsed by the EC
- ✓ To launch a repository of non-English guidelines will be considered in the future.
- ✓ The gathering of local guidelines and documents is interesting for the identification of limitations imposed by local regulations on the implementation of international guidelines.
- ✓ The 44% of the health providers participating in the poll, identified the divergence with national/local regulations as the most limiting factor for the implementation of the guidelines.
- ✓ The guarantee of expert’s panel selection was identified as the most relevant benefit in having the international promoted guidelines in [ERN-EuroBloodNet](#) (55%). The identification of Conflict of interest was the less relevant for the audience (6%).
- “ERN-EuroBloodNet e-Learning Platform and Webinars”:
- ✓ Patients with SCD can contact [ERN-EuroBloodNet](#) to be linked to the patients associations.
- ✓ Healthcare professionals and Patients are interested in future educational activities.
- ✓ The audience considered of similar interest the creation of the following material for patients:



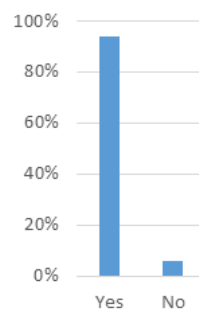
4. Session III: Innovation & Research

The talks of this session focused on the ERN-EuroBloodNet projects developed for a better understanding of Rare Haematological diseases. Firstly, “**ERN-EuroBloodNet Registries**” was provided by [M. Mañú-Pereira](#) ([ERN-EuroBloodNet Scientific Director](#), [Hospital Universitari Vall d'Hebron](#)). [M de la Porta](#) (IRCCS Clinical Institute Humanitas, Rozzano) and M Von Lindern ([Sanguin Blood Supply Foundation](#)) presented “**European funded projects**”. Finally, [P. Fenaux](#) ([Assistance Publique – Hôpitaux de Paris, Hôpital Saint-Louis](#)) was the speaker of the talk “**EuroBloodNet Association sponsoring Clinical Trials**”.

Main Points highlighted during the discussion:

- “ERN-EuroBloodNet Registries”:
- ✓ Interoperability means:
 - to standardized definitions for each point requested in a registry
 - to standardized codes for each point requested in a registry
 - to structure the data (software development)
- ✓ Nowadays, the lack of structure of the electronic health records of centers is a bottle neck for the interoperability achievement,
- ✓ The interoperability scope is focused on registries of the European Member States. The GDPR (legislation) is different between the EU and the rest of non-EU countries blocking the collaboration with individual data between both parties. For this reason, a collaboration with the United Kingdom has been established based on the sharing of aggregated data.
- ✓ Nowadays, a new registry for Cell Dendritic Leukaemia is being developed in ERN-EuroBloodNet. After platform approval, the registry of Cell Dendritic Leukaemia will be available to the rest of the European Union countries.
- ✓ Curators of existing registries can contact ERN-EuroBloodNet for interoperability achievement.
- ✓ Establishing a European Platform for the sharing of minimal data between the different National Registries for the comparison of data at the European level is an interesting project to develop.
- ✓ The 98% of the health professionals answering the poll are able to get the minimal data from the Hospital electronic records.

Are you able to get the minimal data
(number of patients/disease/age)
from your Hospital Electronic Health
Records?



- “European funded projects”:
- ✓ [ERN-EuroBloodNet](#) can contribute by providing support on the clinical part of new research projects. For this purpose, it is essential to present the project to the ERN at the beginning of the proposal preparation.
- ✓ We encourage the 24% of health professionals willing to develop a clinical trial to contact us.

A final talk “Closing remarks & taking home messages” was provided by [M. Mañú-Pereira](#) ([ERN-EuroBloodNet Scientific Director](#), [Hospital Universitari Vall d'Hebron](#)). During the presentation, she informed the audience of different ways to be involved in [ERN-EuroBloodNet](#), and provided the take-home messages.

Main Points highlighted during the discussion:

- ✓ This 2022 will be around 100 Members in ERN-EuroBloodnet.
- ✓ ERNs are long-term initiatives of the EC, for this reason we highlight the relevance of the participation of Members in the actions of their interest.
- ✓ All the actions developed for Cutaneous Lymphoma are a good example of what [ERN-EuroBloodNet](#) can develop.
- ✓ The results obtained in the TCP Mapping highlights the importance of evaluating the standards of care delivered to patients.
- ✓ More opportunities for learning is being developed to Members and Patients; such as more Preceptorships or more Webinars programs.
- ✓ The [ERN-EuroBloodNet website](#) is an essential and free tool for the Rare Haematological Disease community. In order to make the expertise visible, it is very important that the experts of each Member complete their profiles.
- ✓ A memorandum of understanding has been established with the European Hematological Association (EHA) for the development of guidelines and for the development of educational programs.
- ✓ The research component of ERNs is gaining more importance such as an added value to include the proposals that include them.
- ✓ Projects focused on the improvement of the outcome of patients with Rare Haematological Diseases are welcome in [ERN-EuroBloodNet](#).

The 2nd [ERN-EuroBloodNet](#) Progress meeting not only gave an update to the community about the development and results of the on-going projects but also enriched interactions among key stakeholders for new key actions in the field of rare haematological disorders. Presentations of the lectures provided are available at the [ERN Collaborative platform](#).

Experts willing to develop a project in any of the topics developed during the meeting can present a proposal to [ERN-EuroBloodNet](#).

If you are not an [ERN-EuroBloodNet](#) member and are interested in getting the slides please contact maria.rodriguez.sanchez@vhir.org.

THANKS to all for your fruitful participation and valuable contributions! We hope to see more attendants at the next edition! More detailed information will be provided soon.