

Deliverable 5

Report on actions foreseen by educational bodies (EHA and ESH) to address GAPS identified in annual educational programme



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Authors:

Maria del Mar Mañú Pereira – ERN-EuroBloodNet Scientific Director

Victoria Gutierrez Valle – ERN-EuroBloodNet Dissemination & IT Manager

Mariangela Pellegrini – ERN-EuroBloodnet Manager

Béatrice Gulbis - ERN-EuroBloodNet co-Coordinator and non-Oncological Hub chair

Pierre Fenaux - ERN-EuroBloodNet Coordinator and Oncological Hub chair

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1-Background and rationale

Dissemination of knowledge is a priority in order to improve continuous medical education and thereby to provide the highest quality services for patients with Rare hematological diseases (RHD). However, high quality and specialized training courses focused on some RHD, especially those for non-oncological RHD and/or ultra-rare conditions, are infrequent and expensive since

- expertise is scarce and those courses usually involve a high number of international speakers
- they include educational tools, such as webcasting for access on-line after the course and/or televoting educational exercises
- they address a small community.

In addition, curricula for medical specialty training differ from one Member State to another and, in general, little time is dedicated to ultra rare conditions, where an educational action is urgently needed.

These educational gaps directly contribute to the low implementation of good practice guidelines in the field, leading to a variable and sometimes unequal management of patients affected by RHD between countries.

In this context, ERN-EuroBloodNet specific objective 3 aims at disseminating cutting-edge knowledge and facilitate continuous medical education in the field of RHD through the promotion of a blended education (on-site & on-line) for the harmonization of the hematology and pediatric (hematology) specialties curricula throughout the EU. Healthcare professionals in training will directly benefit from blended educational programs since general medical education is not focused enough on the less prevalent RHDs, and specialized training is needed.

Linked to objective 3, the transversal field of action (TFA) on Continuous Medical Education (CME) will aim to spread cutting-edge knowledge and facilitate CME in the field of RHD.

2-Objectives

ERN-EuroBloodNet established five specific objectives as priorities to be accomplished in the frame of the 5 years of implementation, including the specific objective 3: Disseminate cutting-edge knowledge and facilitate continuous medical education in the field of RHDs.

This objective aims to implement a blended educational program (on-site & on-line) with innovative contents and directed by the most outstanding experts in the different types of malignant and non-malignant RHD. It will upgrade medical and scientific education of health care professionals in RHD by incorporating training in best practices and will contribute to the harmonization of hematology and pediatric (hematology) specialties curricula throughout the EU.

In line with the specific objective 3 the present deliverable describes the actions taken and /or foreseen by educational bodies (EHA and ESH) to address GAPS identified in annual educational programme through conferences and training courses contributing to solving inequalities among Member States in the delivery of best care.

3-Methods

3.1 Transversal Field of Action on Continuing Medical Education

The implementation of the ERN-EuroBloodNet action plan has been assured through the establishment of five Transversal Fields of Action (TFAs) in line with each specific objective of the network. In this context, the TFA on Continuing Medical Education was established aiming to implement all tasks and activities related to the achievement of the specific objective 3.

At the beginning of the network, it was agreed that every TFA would be coordinated by one representative from the oncological hub, one representative from the non-oncological hub, and one ePAG representative in order to ensure a balanced coordination of the actions performed. The TFA on Continuing Medical Education is coordinated by:

- Dominique Bron, Jules Bordet Institute- Oncological representative: Professor of Hematology at the Free University of Brussels (ULB) and Head of the department of clinical and experimental hematology at the Institut Jules Bordet, Cancer center of the ULB, in Brussels (Belgium). She was for three years the president of the Belgian Hematology Society. During that period, she organized the national course of excellence in Hematology and was involved in a unique program concerning harmonization of teaching Hematology in Europe (H-NET/EU Program). She remains reviewers for the ELC of the EHA.
- Patricia Aguilar-Martinez, CHU de Montpellier – Non oncological representative: Professor of Hematology at Montpellier University and Head of the department of laboratory hematology Montpellier hospital (France). Includes 3 expert clinical groups (red cells , iron and bleeding disorders), members of Eurobloodnet. Coordinator of a centre of reference (rare red cell disorders) and of a center of expertise (rare iron disorders). President of the French “red cell club” group of the French Society of Hematology. For more than 15 yrs : Collaborations with WHO Human Genetic programme (currently on a project of e-learning) Member and workpackage leader of the ENERCA project during its 4 three-year phases : WP leader for education and training with the elaboration of a e-learning platform on rare anaemias
- Jan Geissler Leukemia Patient Advocates Foundation - ePAG representative: Founder and Managing Director, Patvocates GmbH, Germany. Director, European Patients’ Academy on Therapeutic Innovation (EUPATI). Co-Founder, CML Advocates Network / Vice President Leukemia Patient Advocates Foundation, Switzerland. Chair, Leukaemie-Online / LeukaNET e.V., Germany. He is founder and managing director of

Patvocates, a think tank and consultancy in patient advocacy, acting as advisor on patient advocacy, health policy and social media. For the past 6 years, he has been working for the European Patients' Forum as the Director of the 'European Patients Academy on Therapeutic Innovation' (EUPATI), a project funded by Innovative Medicines Initiative. EUPATI has developed educational material and training courses to educate patient and patient advocates about medicines development processes. He continues to be responsible for EUPATI's future evolution. He is also coordinator of the work package of the new IMI big data project HARMONY, coordinating stakeholder input from patient organisations, HTA bodies, regulators and other stakeholders.

3.2 Collaborations with educational bodies

3.2.1 European Hematology Association (EHA)

The European Hematology Association (EHA) promotes excellence in patient care, research, and education in hematology. The EHA represents one of the core pieces for the creation of ERN-EuroBloodNet and its interest in strengthen collaborations for the Continuing Medical Education programme of the network has been reinforced as ERN-EuroBloodNet develops.

In this context, collaborations ERN-EuroBloodNet and EHA has been established for:

- Providing space for ERN-EuroBloodNet specific meeting at annual EHA congress, as the major event of Hematology at the European level.
- Providing space for ERN-EuroBloodNet/EHA Capacity Building for Patient Advocates at the EHA congress.
- Providing an ERN-EuroBloodNet both at the dissemination area within the annual EHA congress, which represents a huge opportunity for spreading the hematology target groups the objectives and results of the network.
- Analysing the next steps for the identification of gaps in education at the RHD field.

In addition, the ERN-EuroBloodNet Independent Advisory Board includes Carin Smand, EHA Executive Director, as contact person providing advice in the educational field within the EHA.

3.2.2 European School of Haematology (ESH)

The European School of Haematology (ESH) is a not-for-profit institution for continuing education founded in 1985 to promote and facilitate access to state-of-the-art and cutting-edge knowledge in haematology and related disciplines at the European level. ESH Conferences

present state-of-the-art science and insight into new developments in the fields of basic, clinical and therapeutic research in Haematology.

ESH has deeply contributed to the plan undertaken within the ENERCA project. One of the main activities implemented in the field was the co-organization of two training courses:

- “Training course on haemoglobin disorders: laboratory diagnosis and clinical management” was held in Barcelona, Spain, the 23-24 January 2015. It was attended by 160 participants from 36 different countries.
- “Training course on diagnosis and management of very rare red cell and iron disorders” was held in Lisbon, Portugal, the 29-30 January 2016. It was attended by 150 participants from 29 different countries.

The fruitful collaboration ESH-ENERCA given place to one of the biggest outcomes of ENERCA project, not only for the organizers but also for the attendance. Evaluation sheets distributed to all participants: Most talks were rated +1 (very good) or +2 (outstanding). 90% of participants replied that the course met their learning objectives. In addition, webcasting of the presentations are available through ENERCA and ESH website allowing those interested professionals or students not able to attend the courses benefit from them.

In line with the previous collaboration, ESH is one of the scientific societies cornerstone for both, the analysis of needs in the educational area concerning RHD and implementation of the training courses foreseen in the frame of the network.

In this context, the ERN-EuroBloodNet Independent Advisory Board includes Didi Jasmin, ESH Executive Director, as contact person providing advice in the educational field within the ESH.

4 - Identification of educational GAPS

The methodology for the gathering of educational needs in the field of RHD were analysed among ERN-EuroBloodNet, EHA and ESH. Several approaches were identified:

4.1 ERN-EuroBloodNet approach: TFA targeted online questionnaire

After an analysis undertaken by the ERN-EuroBloodNet coordination team, a common need across all TFAs was identified regarding the need for the gathering of available services/activities/resources within the network available for RHD. In order to address this need, a transversal methodology was defined by the coordination team including a set of online questionnaires to be conducted among ERN-EuroBloodNet members encompassing the different key items of each of the TFAs.

TFA targeted online questionnaires were agreed to be endorsed in ERN-EuroBloodNet website in order to facilitate the gathering of answers from the members and their analysis. As a result, all the different gaps within the TFAs will be identified and planned to be addressed in the coming annual work plans.

In order to get the maximum number of answers from the experts on RHD, especially for those ultra-rare RHD, the launch of TFAs questionnaires was agreed to be performed once the inventory of ERN-EuroBloodNet members and experts was finalized, as they are the target group.

The main objective of the questionnaire for the TFA on Continuing Medical Education is to compile all the existing e-learning platforms and the post-graduate courses for RHD. The on-line agreed to be implemented include:

1. Title
2. Type of activity
3. Available at (eg. Link if available on-line)
4. Promotor (name of scientific society, institution, individual...)
5. Language
6. To which "Disease/group of diseases" apply? (based on ORPHA codes)

7. Which areas of health care services are covered?
 - Diagnosis
 - Prevention
 - Therapy /Clinical management
 - Research
 - Diffusion and raise awareness
8. Activity addressed to
 - Health care professionals
 - Researchers
 - Patients
9. Activity delivery format
 - Onsite
 - Live broadcast online
 - e-Learning platform
 - Blended (onsite&online)

Based on the analysis of the survey results a report will be produced on existing eLearning platforms and post-graduate courses on RHD according to the Orpha classification. Accordingly, promotion of new eLearning platforms and of development of post-graduate courses will be prioritized in order to address the educational GAPS identified.

4.2 EHA approaches

4.2.1 Approach 1 - Online survey

Goal

The goal of conducting a survey is to obtain specific information on the educational needs in RHDs as perceived by hematologists and by Key Opinion Leaders (KOLs) in specific hematological disorders.

Method

A short online survey could be conducted among hematologists working in Hematology Centers of Expertise members of the ERN-EuroBloodNet as well as in general and academic healthcare providers. These hematologists would be asked to identify their educational needs in RHD, per

disease area. To identify these disease areas, the EHA Hematology Curriculum can be used as a basis, combined with the Orpha classification of RHDs. To ensure proper representation of each EU country, per country a group of hematologists (2-10, depending on the size of the country population) would be selected to participate in this survey.

A second target group, KOLs, could be asked which rare diseases, according to them, are not sufficiently/adequately addressed in their national curriculum (taking into account that KOLs represent Centers of Expertise in only 15 Member States and may not be aware of the curriculum in other countries).

After analysis of the survey results a report on educational needs in RHDs would be produced, that would be structured according to the Orpha classification and linked to the EHA Hematology Curriculum. Based on this the educational needs in RHD will be prioritized followed by additional research on how to best create and deliver education for this.

Advantages

By combining the database EHA has available of hematologists in Europe including their specialty, and the database ERN-EuroBloodNet has available on Hematology Centers of Expertise, such a survey is probably relatively easy to conduct.

Disadvantages

The expected outcome is a long list with very specific conditions (the Orpha classification includes over 450 rare hematological diseases). Therefore, the usefulness of the results could be doubted, as it will be a challenge to facilitate continuous medical education to fill all these very specific gaps.

4.2.2 Approach 2 - Embed RHDs in existing meetings

Goal

EHA and ESH are organizing several educational and scientific meetings each year, covering a variety of hematological disease areas. Embedding RHDs in these meetings would make it possible for the participations to learn about RHDs in the disease area they are interested in. In addition, questions could be added to the meeting evaluation surveys, asking for educational needs in RHDs.

Method

An overview of meetings would be created. For each meeting, the meeting chairs can be asked to add RHDs to their program e.g. by involving RHD experts in the composition of the program. The ERN-EuroBloodNet subnetwork coordinators can be asked to look into the existing programs and recommend which topics could be added.

Targeted promotion of these meetings, especially regarding the RHDs that will be part of the program is a pre-requisite.

Advantages

It would be relatively easy to implement, as it builds on the existing meeting structures.

As the organized meetings cover a variety of disease areas (malignant and non-malignant), a broad spectrum of RHDs can be addressed.

Disadvantages

Due to the large number of RHDs, there will still be specific RHDs that are not represented.

4.2.3 Approach 3. Classifying online learning material as RHD material

Goal

EHA has an online Learning Center, which includes a wide variety of congress webcasts, presentations, expert interviews, clinical cases etc. Including a special 'RHD mark' would make it easier to find materials related to RHDs. Subsequently, the user statistics can be analyzed. This would give insight in the most visited topics.

Method

In order to implement such an 'RHD mark', the following steps would need to be taken:

1. Classifying the existing and new online learning materials
2. Technical development of the online platform, to allow the RHD mark to be attached and displayed.

Advantages

This approach would enable hematologists to find online educational materials on RHDs in a mouse click. Raising awareness regarding this new feature on the EHA Learning Center as well as collecting and analyzing user statistics specifically on RHDs would provide an indication of the educational needs in this area. These needs would be used as a basis to further expand online learning tools in specific areas.

Disadvantages

Classifying all materials would be a time-consuming task and requires availability and commitment of experts willing to do this task.

The technical developments needed would require a certain budget.

5-Conclusions and next steps

One of the objectives of ERN-EuroBloodNet is to disseminate cutting-edge knowledge and facilitate continuous medical education (CME) in the field of RHD. For this aim, collaborations with educational bodies as EHA and ESH will be essential, not only for the gathering of gaps of educational needs, but also for its analysis and posterior prioritization of areas needed for

Main next steps foreseen to be taken in the coming years of the network are:

- 1. Implementation of the online targeted questionnaire for the TFA on continuing medical education.**

TFA targeted online questionnaire will be loaded on to the ERN-EuroBloodNet website in order to gather key essential information from the members targeted to existing activities/services/initiatives related to the provision of medical education.

The questionnaire will provide the basis for the analysis of expertise and trainee of members of the multidisciplinary teams involved in ERN-EuroBloodNet members and other HCPs and Affiliated partners while mapping the training activities and eLearning platforms implemented for the RHDs community.

In result, the questionnaire will gather all the activities performed at EU level leading to the identification of the main gaps in education. Accordingly, promotion of new eLearning platforms and of development of post-graduate courses will be prioritized in order to address the educational GAPS identified.

The expected outcomes include:

- a) The facilitation of the harmonization of the haematology and paediatric (haematology) specialities curricula throughout the EU - European haematology curriculum/passport.
- b) The improvement of continuing medical education on ultra-rare haematological diseases among European health professionals whatever their country of practice.
- c) The promotion of diffusion and implementation of existing guidelines in the diagnosis and clinical management of ultra-rare haematological diseases, as well as existing recommendations in the field.

2. Identification of areas including highly specialized procedures requiring short stays for the acquisition of expertise.

Some Highly specialized procedures will require not only lessons but also practical exercises for their full implementation, eg HSCT. Based on the results of the targeted online questionnaire and on the feedback from subnetwork coordinators, areas for on-site training and experts centres related, will be identified and invited to offer short stays in order to strengthen professional relations and common practices.

3. Analysis on the approaches identified by EHA

The approaches identified by EHA are very different and require further investigation by ERN-EuroBloodNet coordination team and TFA on Continuing medical education coordinators in terms of feasibility, scope, time lines and budget. EHA has offered to facilitate such a discussion.

Subsequently, the most favorable approach can be worked out in detail, with a well-defined and realistic timeline for coming years of the network to be agreed upon by EuroBloodNet, EHA and ESH. The following overview was provided by EHA for considering the suggested approaches:

- Approach 1. Online survey
 - It should be investigated if the 450 specific RHDs could be grouped or prioritized, in order to obtain more concrete and useful results.
 - It needs to be determined how to select the respondents.
- Approach 2. Embed RHDs in existing educational and scientific meetings
 - Based on the list of EHA and ESH meetings scheduled for 2018 and 2019 it needs to be defined which RHDs would be a logical addition to the meeting programs.

Note: This approach does not rely on a needs analysis but more on the expert opinion of KOLs regarding which issues should be specifically addressed in meeting programs.

- Approach 3. Classifying online learning material as RHD material
 - An estimation needs to be made for the time needed to classify the learning materials as well as identifying experts who could do this.
 - A quotation needs to be requested for the costs of the necessary technical developments.

4. Gathering of the needs reported by patients

A set of recommendations will be elaborated based on the results of patients' surveys on expectations on Centers of Expertise and impact of the disease in daily life that will be undertaken by TFA on Cross border health.

In addition, the ERN-EuroBloodNet website will endorse a system for patients voices (SPV) for reporting patients' experiences and adverse events that may complement the results from the survey.

5. To implement a blended educational program (on-site & on-line) based on gaps identified

Agreements will be reached with educational bodies (EHA and ESH) in order to address the educational gaps and priorities identified through their conferences and training courses.

6. Co-organization with the ePAGs of European symposia with interactive patient participation.

An agreement was reached with ePAGs representatives following their demand to not duplicate number of symposiums for patients but collaborate with the EHA to reinforce the sessions dedicated to patients celebrated within the EHA congress. Accordingly, ERN-EuroBloodnet and ePAGs will collaborate in the organization of the European Symposium on RHD to be organized within the 23rd EHA congress in Stockholm from June 14-17, 2018.