

## DELIVERABLE 5.1 ERN-EUROBLOODNET REPORT ON MONITORING EXERCISES

**European Reference Network on Rare Hematological Diseases  
ERN-EuroBloodNet**

EUROPEAN REFERENCE NETWORKS  
FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

**Share. Care. Cure.**



## DOCUMENT INFORMATION

### DELIVERABLE 5.1 ERN-EuroBloodNet REPORT ON MONITORING EXERCISES

Report document

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Authors:

**Alanna Irving - ERN-EuroBloodNet Monitoring Manager**

**Victoria Gutiérrez Valle – ERN-EuroBloodNet Scientific Manager**

**Maria del Mar Mañú Pereira – ERN-EuroBloodNet Scientific Director**

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

**Pierre Fenaux - ERN-EuroBloodNet Coordinator and Oncological Hub chair**

#### Short Description

Report (EN) on ERN-EuroBloodNet monitoring exercises and analysis of the evolution of the network through the indicators compiled

#### Disclaimer:

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## LISTS OF ABBREVIATIONS

CDMT – Clinical Decision-Making Tool

CPG – Clinical Practice Guidelines

CPMS – Clinical Patient Management System

ERN – European Reference Network

EU MS - European Union Member State

HCP – Healthcare Provider

MS – Member State

RHD – Rare Haematological Diseases

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# 1. INTRODUCTION

## ERN-EuroBloodNet

ERN-EuroBloodNet seeks to guarantee that European citizens affected by Rare Haematological Diseases (RHD) benefit from the same level of highly specialised care, thereby improving their overall quality of life and reducing inequalities in access to healthcare across Europe.

ERN-EuroBloodNet's objectives include:

- Improving equal access to highly specialized healthcare delivery for RHD
- Pooling expertise and best practice in prevention, diagnosis and clinical care
- Facilitating continuous medical education
- Fostering cooperation in the development of therapies, clinical trials and methodologies.

## EUROPEAN REFERENCE NETWORKS MONITORING SYSTEM

The European Reference Networks (ERN) legal framework sets out the objectives, principles and criteria of the ERNs, as well as processes for their implementation and evaluation:

- Commission Delegated Decision 2014/286/EU, defining the criteria and conditions that healthcare providers and the ERNs should fulfil
- Commission Implementing Decision 2014/287/EU, defining criteria for establishing and evaluating ERNs
- Commission Implementing Decision 2019/1269 amending implementing decision 2014/287/EU

The ERN Continuous Monitoring and Quality Improvement System (ERN CMQS) has four strands of work:

- I.- Continuous monitoring of the Common Core set of ERN 18 Indicators (common to all ERNs)
- II.- ERN specific set of indicators (by ERN). Including Network specificities and addressing outcomes (clinical and not clinical)
- III.- ERN extended set of indicators (HCP indicators applications 2016). Periodical self-assessment and reporting of the ERNs and HCPs
- IV.- External (MS or third parties) validation of HCP fulfilment of the criteria (specific criteria) for healthcare providers defined in the HCP membership applications (2016)

The first of these comprise ERN continuous monitoring, where Monitoring Exercises are carried out every year, and a full Evaluation every five years.

Monitoring Exercises are based on a set of 18 indicators built by the ERN Continuous Monitoring Working Group of the Member States and ERN Coordinators. These indicators were defined following an extensive consultation process and agreed by the ERN Board of Member States and ERN Coordinators Group in September 2018, and have undergone a series of revisions and refinements. The IT unit of DG SANTE developed a web-based data collection system that went live in January 2019.

Specific objectives of the ERN monitoring system are:

- Provide transparency and reassurance to the rare disease patient community and the public of the expertise within the networks, that care is safely delivered and that there is improved access to quality of diagnosis, care and treatment
- Help ensure consistency across assessments of the Networks and Healthcare providers, support the self-assessment process and promote ongoing quality improvement.
- Show Member States and legislators that the ERNs benefit patients (accountability)
- Allow for timely identification of areas for improvement
- If necessary, foster organisational change or adjustments in strategy
- Promote patient empowerment: when information is released, citizens use it and can make more educated choices
- Request the further support of Member States to the ERNs' system when it is not possible to meet objectives due to lack of resources

## 2. MONITORING EXERCISES: CONDUCTION AND PARTICIPATION

### GLOBAL OVERVIEW

ERN-EuroBloodNet Monitoring Exercises are carried out by the coordination team, and based on Excel templates that are circulated among Member and Affiliated Partner Healthcare Providers (HCPs). Data has been submitted to the European Commission as follows:

1. 2017 annual data; submitted March 2019
2. 2018 annual data; submitted October 2019
3. 2019 semester 1 data; submitted February 2020
4. 2019 semester 2 data; submitted April 2020
5. 2020 semester 1 data; submitted October 2020
6. 2020 annual data; submitted March 2021
7. 2021 semester 1 data; submitted November 2021
8. 2021 semester 2 data; submitted April 2022
9. 2022 annual data; submitted May 2023

The main difficulties in conducting Monitoring Exercises have concerned the bureaucratic burden on Members in collating data from different sources under time pressure, and confusion over definitions of terms in the indicators themselves, particularly indicators 2.1 (number of new patients), 7.1 (presentations of the ERN) and 5.1 (clinical trials and observational studies), as well as 4.2 (accredited training activities), 6.1 (Clinical Practice Guidelines adopted) and 6.2 (Clinical Practice Guidelines and Decision-Making Tools written).

Processes of continuous feedback mechanisms via the Monitoring Working Group have resulted in clarifications of indicators and refinement of criteria. Some of these changes to criteria have expanded what can be reported under indicators – for example, clinical trials that were previously ineligible due to lack of acknowledgement of the ERN can now be amended with an annexed letter of acknowledgement and will be eligible to be reported.

Participation of ERN-EuroBloodNet HCPs in Monitoring Exercises shows improvement across the years, although the participation of Affiliated Partners has been more erratic:

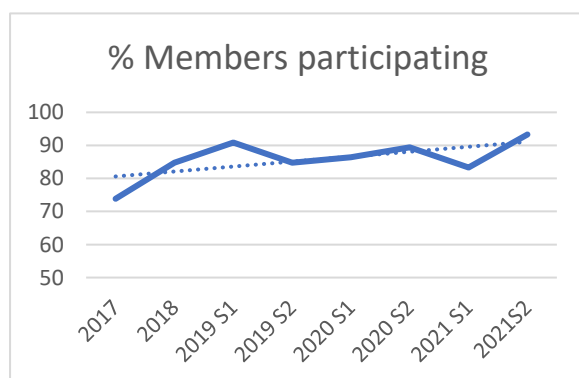


Figure 1: Percentage of ERN-EuroBloodNet Members participating in Monitoring Exercises

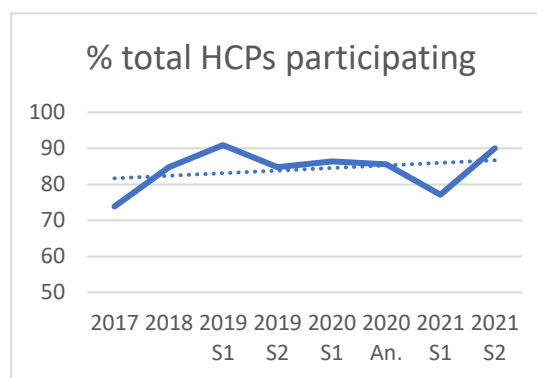


Figure 2: Percentage of all ERN-EuroBloodNet Healthcare Providers (Members + Affiliated Partners) participating in Monitoring Exercises

	2017	2018	2019 S1	2019 S2	2020 S1	2020 Annual	2021 S1	2021 S2	2022
Members	48/65	56/66	60/66	56/66	57/66	59/66	50/60	56/60	85/96
APs	-	-	-	-	-	6/10	4/10	7/10	4/7

Table 1: HCP responses (out of total HCPs) to Monitoring Exercises 2017-2022

## MONITORING EXERCISE 2022

ERN-EuroBloodNet covers more than 450 RHD, which have been grouped into 77 disease groups according to the expertise and procedures required for appropriate healthcare provision. The aim of defining these disease groups was to standardize the collection of data, particularly number of patients and new patients, in order to improve granularity and comparability. Due to limitations of the application form and idiosyncrasies across countries and HCPs, diseases have thus far been grouped differently by different Members, which limits how well the data can be exploited for insights.

The Monitoring Exercise carried out in April 2023 gathered data for 1 January - 31 December 2022, via excel templates sent to all Members and Affiliated Partners requesting the following information:

- Total number of new patients in all disease groups covered
- Relevant training activities delivered by HCP teams
- Relevant clinical trials participated in that were open in 2022
- Relevant observational studies participated in that were open in 2022
- Relevant articles published in peer-reviewed journals in 2022
- ERN-EuroBloodNet-endorsed CPGs and CDMTs implemented in the HCP
- Presentations of ERN activities delivered in 2022
- Experts' contact details for the HCP team

This was a broader exercise than in previous years, where only of new patients were requested. The intention of this expanded data collection was to more accurately capture the extent of Members' activities. Due to strict adherence to the criteria established in the Monitoring Indicators, few clinical trials, observational studies and publications were reported in the initial years of the ERN; in order to improve performance of these indicators, a strategy was developed to collect wider data on the activities of Members and cross-reference to identify activities that could be eligible, e.g. by including an acknowledgement of the ERN. This would also allow the identification of particularly prolific Members, which would allow targeted future actions promoting better adherence to criteria, and thus improved reporting possibilities in future years.

A final aim of the data collection exercise was to enable the completion of ERN-EuroBloodNet's repository of experts, a searchable database of experts belonging to ERN-EuroBloodNet HCPs.

Participation in this exercise was lower than in previous years: 85 out of 96 Members and 4 out of 7 Affiliated Partners responded partially or fully.

The decrease of the participation is likely due to several reasons:

- For the original 60 Member HCPs, the Monitoring exercise came immediately after a comprehensive and strenuous Evaluation exercise, and several Members were still undergoing preparations for an on-site audit in relation to this at the time of the Monitoring.
- For the 36 new Members, this was the first Monitoring exercise undertaken since the application process in 2019, and so there were many uncertainties in navigating a new process.

Those HCPs who found it too burdensome to report on all indicators were advised to prioritize data on total patients and new patients. Adherence to the new disease groups was not mandatory for this exercise, but would be in subsequent years. Of the 85 Members who responded, 59 gave both patient data and data on one or more additional activity (education, trials, studies and publications), 19 sent only patient data, and 7 sent patient data plus some information on guideline implementation and expert contact details. 5 of the responding Members re-organised their data to fit the newly defined Disease Groups.

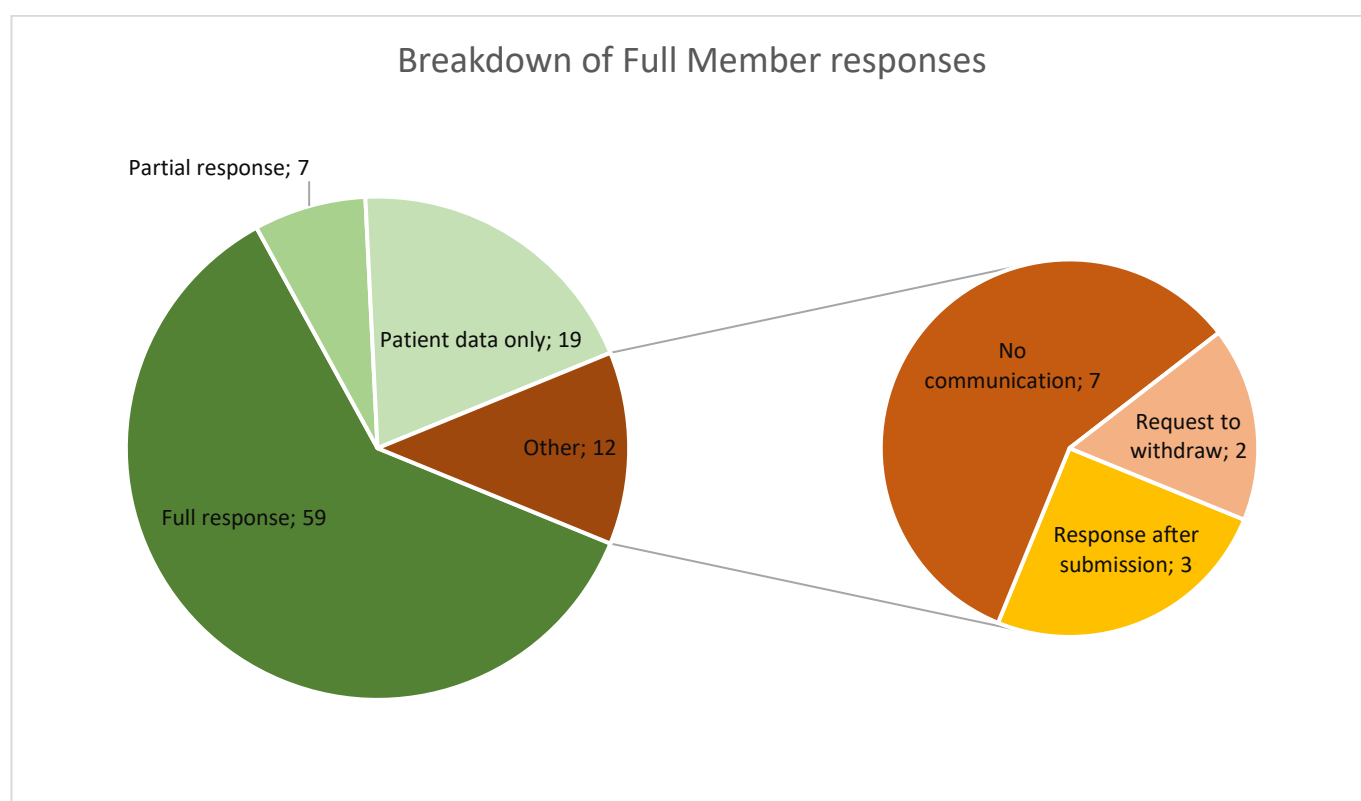


Figure 3: Breakdown of Member responses to 2022 Monitoring Exercise

Several Members complained about the burden of the task, and 2 requested to discontinue Membership. 2 New Members returned data after the Monitoring Exercise had been submitted and so were not included; 7 Members did not respond to any communications, of which 4 were New Members and 3 were existing Members.

Of 7 Affiliated Partners, 2 sent full responses, 2 sent patient data only, and 3 did not respond to communications.



### 3. RESULTS

Performance across all indicators has improved over the 5 years of the ERNs' activity, which reflects the growth of the network, both in terms of Membership, and in terms of resources to devote to new actions.

#### MEMBERS AND NUMBER OF NEW PATIENTS

ERN-EuroBloodNet's ultimate aim is to ensure equal access to specialized healthcare and expertise for all patients with RHD in the European Union. Therefore, it seeks to incorporate expertise on all disease groups within the scope of the ERN in as many EU Member States as possible, in order to achieve comprehensive geographical coverage. This coverage can be analysed at the level of Members and Affiliated Partners, subnetworks, or diseases groups.

Since 2017, coverage has increased, incorporating more Members and more Affiliated Partners in more Member States, as well as expanding the disease coverage of some existing members. Accordingly, the number of patients falling within the remit of the ERN has increased over time.

As of 2023, ERN-EuroBloodNet has 96 Member Healthcare Providers in 18 EU Member States, as well as 7 Affiliated Partner Healthcare Providers in 6 Member States: a total of 103 HCPs in 24 Member States. Currently, Croatia, Latvia and Romania have no Member or Affiliated Partner representation within the ERN.

No.	Monitoring Indicator	2017	2018	2019	2020	2021	2022
1.1	Number of Member States with Health Care Providers as Full Members or Affiliated Partners in the ERN	15	15	15	23	22	24
1.2	Number of Full Members of the ERN	65	66	66	66	60	96
1.3	Number of Affiliated Partners in the ERN	0	0	0	10	20	7
	Total number of Health Care Providers represented in the ERN	65	66	66	76	70	103
2.1	No. new patients	8104	9069	11563	10093	11669	16492

Table 2: Monitoring Indicators 1.1, 1.2, 1.3 and 1.4, 2017-2022

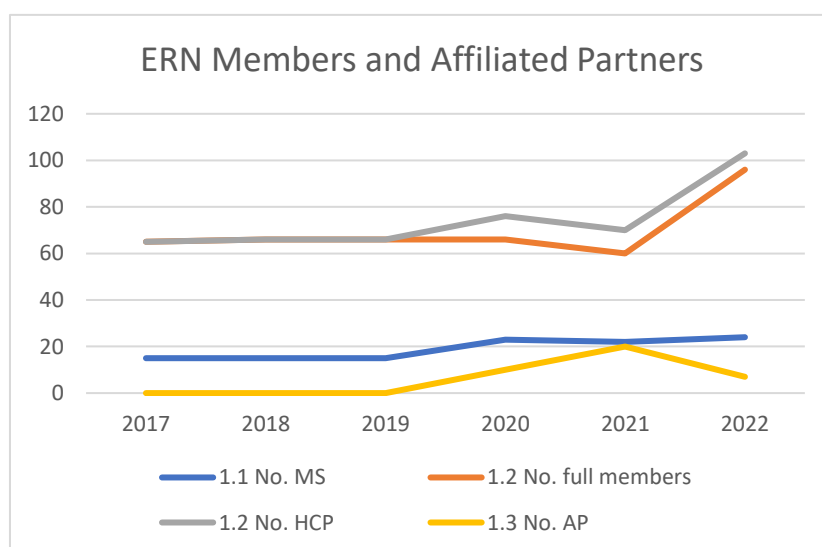


Figure 4: Results of indicators 1.1, 1.2 and 1.3 from 2017 - 2022

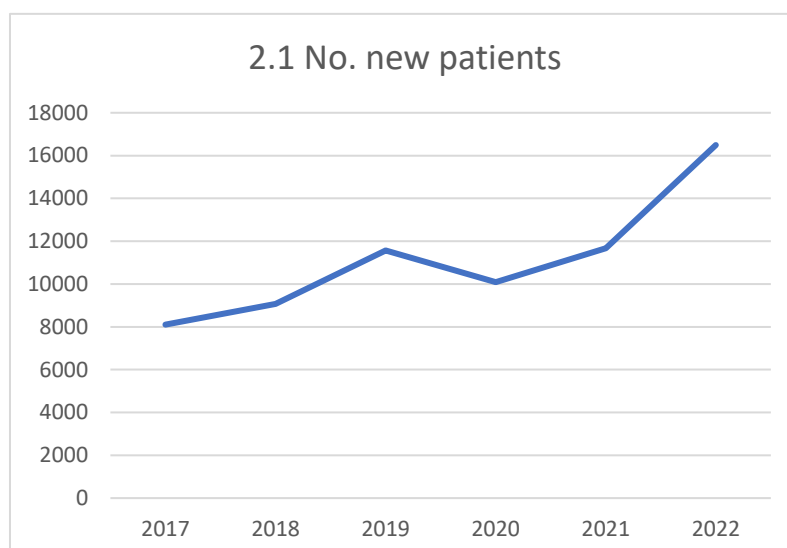


Figure 5: Number of new patients within ERN-EuroBloodNet 2017 - 2022

The decrease in Member States and HCPs from 2020 to 2021 reflects the discontinuation of UK HCP membership with Brexit; the decrease in Affiliated Partners from 2021 to 2022 is due to HCPs moving from Affiliated Partner to Full Member.

The 2022 Monitoring Exercise collected 16423 new patients reported by 85 Member HCPs (87.5% participation), and 69 new patients reported by 4 Affiliated Partners. 77 Members reported data for all disease groups covered; 8 reported data with one or more disease groups missing. 2 sent responses after the Monitoring Exercise was submitted; 10 did not report any data.

Breaking down these figures by subnetwork gives the following results:

Subnetwork	No. New Patients	No. Members reporting	Total Members in subnetwork	% participation
Red Blood Cell defects	2265	48	52	92.3%
Bone Marrow Failures	568	36	40	90%
Haemochromatosis and iron disorders	153	21	24	87.5%
Bleeding and coagulation disorders	3494	45	50	90%
Lymphoid malignancies*	4461	36	43	83.7%
Myeloid malignancies*	5483	37	43	86%

Table 3: Number of new patients per subnetwork reported in 2022 Monitoring

\*2 HCPs reported a figure for total lymphoid/myeloid patients, which are included in "lymphoid" in this table (412 patients in total).

Breaking down the data by Member State gives the following results:

Member State	No. New Patients	No. Members reporting	Total Members in Member State	% participation
Belgium	636	6	6	100%
Bulgaria	5	2	2	100%
Cyprus	53	1	1	100%
Czech Republic	625	3	3	100%
Germany	2277	8	11	72.7%
Denmark	621	2	2	100%
Spain	445	3	4	75%
Finland	34	1	1	100%
France	2160	10	13	77%
Greece	340	4	4	100%
Hungary	253	1	1	100%
Ireland	44	1	1	100%
Italy	5224	31	34	91.2%
Lithuania	753	1	1	100%
The Netherlands	1944	6	6	100%
Poland	653	1	2	50%
Portugal	76	2	3	66.6%
Sweden	280	1	1	100%

Table 4: Number of new patients per EU MS reported in 2022 Monitoring

## PATIENT INVOLVEMENT

It is crucial to ensure the meaningful involvement of patients of all diseases within scope in the decisions and activities of the ERN, in line with the importance of patient-centred care.

The coordination team has carried out continuous monitoring of which patients organizations have been involved, their geographical coverage, their disease coverage, the type of activity they participate in and how often (e.g. a one-off action, contribution to a longer-term project, or permanent member of a decision-making body). This information is available on the [ERN-EuroBloodNet website](#).

Monitoring Indicator	2017	2018	2019	2020	2021	2022
1.4 Number of patient organisations represented in the ERN	7	11	36	73	58	52

Table 5: Monitoring Indicator 1.4, 2017-2022

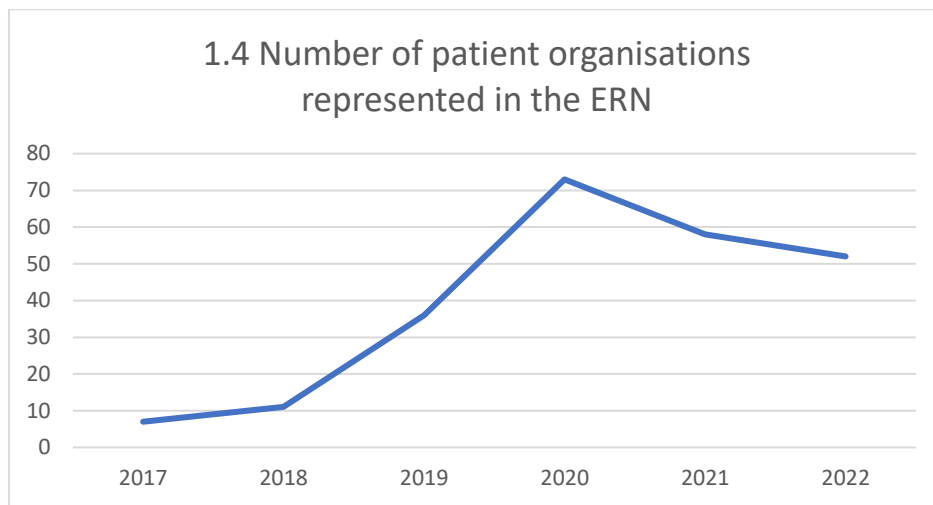


Figure 6: Number of patient organisations represented in ERN-EuroBloodNet 2017-2022

From the 52 patient organisations reported in 2022, 19 are umbrellas:

- |   |  |
|---|--|
| 1. EURDIS (EU/Multinacional)                  | 11. Lymphoma Coalition (EU/Multinacional).     |
| 2. Leukemia Patient Advocates Foundation (EU) | 12. CML Advocates Network (International)      |
| 3. TIF (EU/Multinacional)                     | 13. Gascdo (International)                     |
| 4. MDS UK PatSupport Group (National)         | 14. FMDT SOS Globi (National)                  |
| 5. MDS Alliance (EU)                          | 15. SCD Association of America, USA (National) |
| 6. Latvia Hemophilia Society (National)       | 16. SCD Association of Canada (National)       |
| 7. European Haemophilia Consortium (EU)       | 17. PESCA (EU)                                 |
| 8. Latvian Alliance of RD (EU/Mul)            | 18. SC Society Ireland (National)              |
| 9. PNH support (EU)                           | 19. ESCF (EU)                                  |
| 10. EFAPH (EU)                                |  |

## CPMS

The use of the CPMS system as a means to provide cross-border, multi-disciplinary expert healthcare advice has encountered some difficulties, including technical barriers, and loss of staff within the coordination team dedicated to promoting and supporting the use of the system. It is hoped that by being involved in the redesign of the system and launching pilot schemes, some of these barriers can be overcome to increase use in the future.

Monitoring Indicator	2017	2018	2019	2020	2021	2022
2.2 Number of patients enrolled International CPMS	4	7	13	12	7	2
3.1 Number of CPMS case panels reviewed (urgent/non-urgent)	0/3	1/6	1/10	3/9	0/1	0/0
3.2 Time taken to provide multidisciplinary advice (urgent/non-urgent)	0/0	0/150	12/299	29.3/73.8	0/147	0/0

Table 6: Monitoring Indicators 2.2, 3.1 and 3.2, 2017-2022

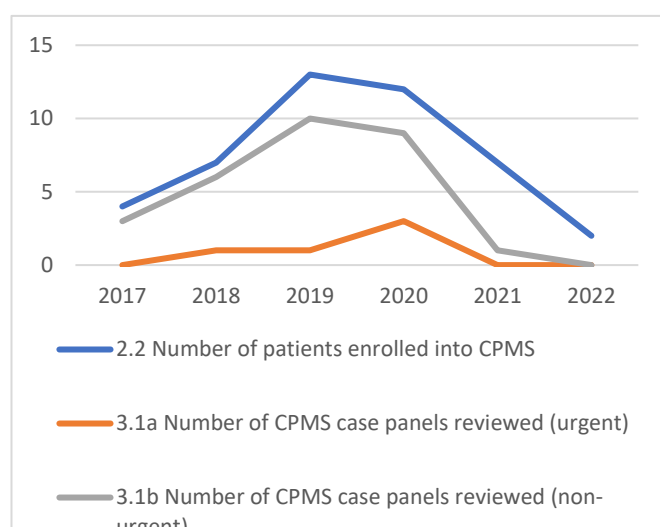


Figure 7: CPMS patients and panels 2017-2022

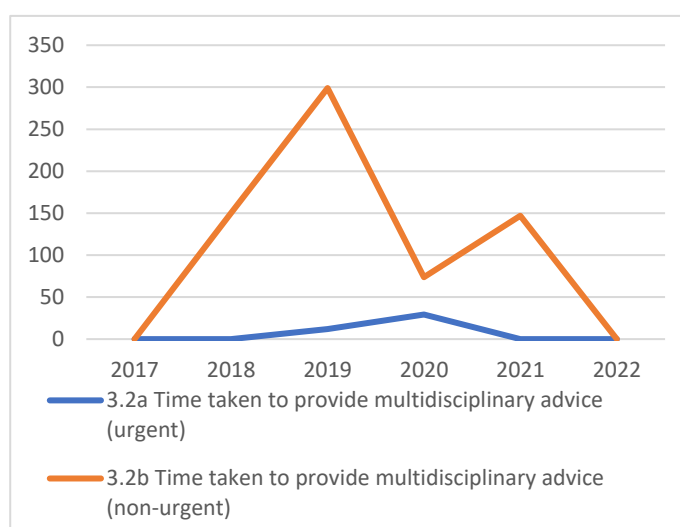


Figure 8: Mean CPMS panel length (days)

## EDUCATION

The number of educational activities, both accredited and non-accredited, has increased with the launch of educational programmes, including:

- Thursday Webinars, for [healthcare professionals](#) and for [patients](#);
- Topic on Focus, for [healthcare professionals](#), for [patients](#), and for [patients' organisations](#); and
- [preceptorships](#) for healthcare professionals.

Activities are tracked by the coordination team, detailing:

- the Intended audience,
- the type of activity (e.g. webinar, video),
- the HCPs involved as coordinator or speaker (and therefore reported as participating).

All training materials are available on the [ERN-EuroBloodNet EDU Blood Academy](#) on the website.

Monitoring Indicator	2017	2018	2019	2020	2021	2022
4.1 Number of non-accredited educational activities (activities/HCP)	0	1	0/0	36/25	87/19	83/15
4.2 Number of accredited educational activities (activities/HCP)	0	0	0/0	23/13	3/6	31/14

Table 7: Monitoring Indicators 4.1 and 4.2, 2017-2022

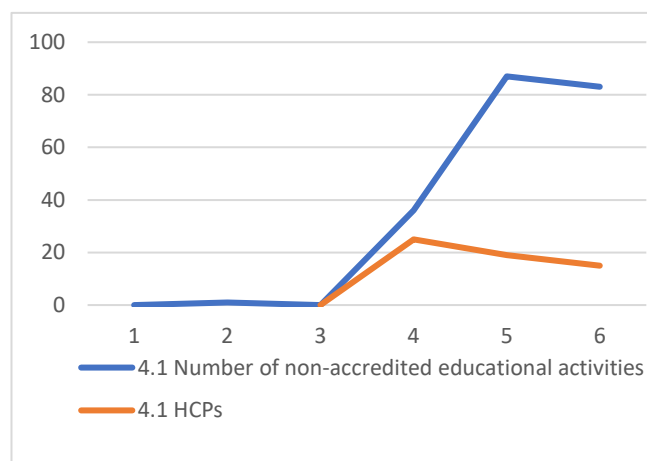


Figure 9: Number of non-accredited educational activities and HCPs involved 2017-2022

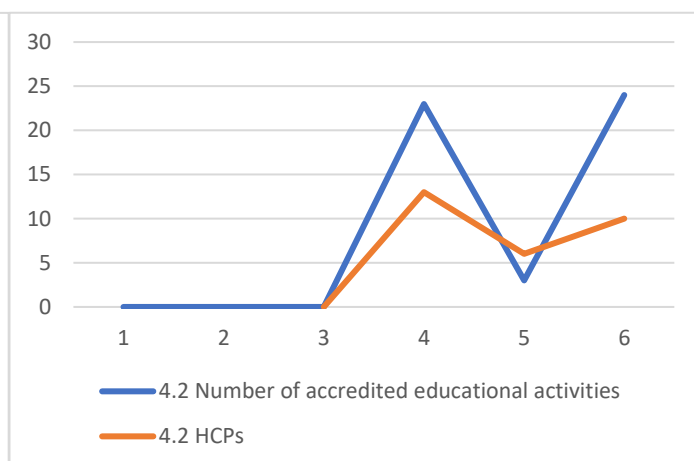


Figure 10: Number of accredited educational activities and HCPs involved 2017-2022

In 2022, 83 non-accredited activities involving 15 HCPs and 31 accredited activities involving 14 HCPs were delivered. 1 of these accredited activities was identified through the data collection from Members.

The breakdown of Members' involvement education activities per Member State is as follows:

Member State	Number of non-accredited training activities	Number of HCPs involved	Number of accredited training activities	Number of HCPs involved
Belgium	2	1	1	1
Bulgaria				
Cyprus	1	1	1	1
Czech Republic				
Germany			4	3
Denmark				
Spain	1	1	2	1
Finland				
France	12	4	8	1
Greece			1	1
Hungary				
Ireland				
Italy	5	6	13	6
Lithuania				
The Netherlands	1	1		
Poland				
Portugal	2	1		
Sweden				

Table 8: Non-accredited and accredited training activities per EU MS reported in the 2022 Monitoring

Due to limitations on the ability to disseminate the logo and other materials without signed partnership agreements from all newly incorporated Members, the number of activities that meet eligibility criteria to be reported under Monitoring Indicators is lower. However, the exercise has raised awareness among Members and New Members of the need to include the logo in training activities and presentations, and once they can be supplied with the necessary materials, these numbers are expected to increase.

## RESEARCH ACTIVITIES

Research activities, including clinical trials, observational studies, and peer-reviewed publications, have been difficult to report due to changing or ambiguous indicator criteria, which have been interpreted differently by different ERNs. Strategies are in place to better identify relevant activities and promote adherence to criteria, ultimately to improve reporting and therefore better represent the extent of activities within the ERN.

ERN-EuroBloodNet has strictly adhered to eligibility criteria of Monitoring Indicators when counting activities:

- 5.1a - Number of unique clinical trials involving at least two ERN Members from at least two different Member States, that acknowledge the ERN, either ongoing or finalized during the reporting period.
- 5.1b - Number of unique observational prospective studies (including academic and industry-driven studies), observational cohort studies, case control studies or case-series studies that involve at least two ERN Members from at least two different Member States, that acknowledge the ERN, either ongoing or finalized during the reporting period.
- 5.2 - Number of unique peer-reviewed publications accepted for publication in accredited scientific journals during the reporting period regarding disease groups falling within the scope of the ERN, that acknowledge the ERN and have as major contributors at least two Members from at least two Member States.

By cross-referencing Members' responses to the expanded data collection in 2022, plus searching for "EuroBloodNet" in clinical trials.gov and pubmed.ncbi.nlm.nih.gov, the following were identified:

- 164 clinical trials open in 2022 involving more than one Member HCP, of which;
  - 134 involved HCPs from more than one Member State;
  - 1 included an acknowledgement of ERN-EuroBloodNet and was therefore reported under indicator 5.1a.
- 18 observational studies open in 2022 involving more than one Member HCP, of which;
  - 16 involved HCPs from more than one Member State;
  - 9 included a reference to ERN-EuroBloodNet and were therefore reported under indicator 5.1b.
- 96 publications published online or in print in 2022 that involved more than one Member HCP, of which;
  - 41 involved HCPs from one Member State only;
  - 1 was published online in 2022 but in print in 2023, and so was discounted for this exercise;
  - 55 articles published in print in 2022 that involved more than one Member HCP from more than one Member State, of which;
    - 6 mentioned the ERN in the affiliation of one or more authors, and were therefore reported officially under Indicator 5.2.
    - 4 were expert recommendations, of which 1 mentioned the ERN in the affiliation of one or more authors, and was therefore also reported under indicator 6.2.

Monitoring Indicator	2017	2018	2019	2020	2021	2022
5.1a Number of clinical trials (trials/HCP)	0	10	0/0	0/0	1/4	1/3
5.1b Number of observational studies (studies/HCP)	0	0	0/0	0/0	7/31	9/41
5.2 Number of peer-reviewed publications (publications/HCPs)	0	2	1/1	0/0	3/12	6/33

Table 9: Monitoring Indicators 5.1a, 5.1b and 5.2, 2017-2022

Details on the reported [clinical trials](#), [observational studies](#) and [publications](#) are available on the ERN-EuroBloodNet website.

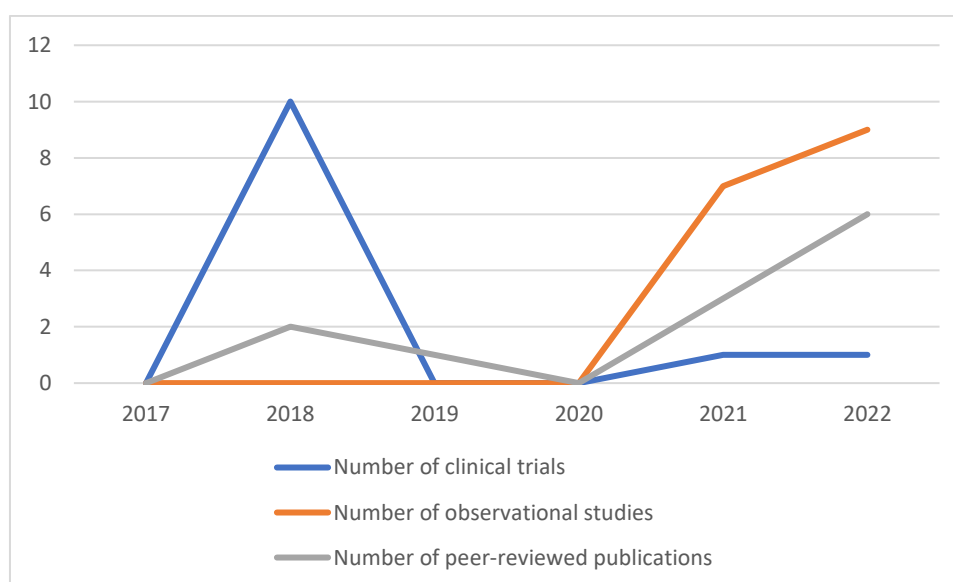


Figure 11: Number of reported clinical trials, observational studies and peer-reviewed publications 2017-2022



The table below shows the breakdown of the research activities reported in 2022 per Member State.

Member State	Number of clinical trials	Number of Members participating	Number of observational studies	Number of Members participating	Number of publications	Number of Members publishing
Belgium			5	5	1	1
Bulgaria						
Cyprus			5	1		
Czech Republic			1	1		
Germany	1	1	5	4	3	6
Denmark			2	1	3	2
Spain	1	1	7	4	2	2
Finland					1	1
France	1	1	5	3	2	6
Greece			1	2		
Hungary						
Ireland			1	1		
Italy			6	21	6	10
Lithuania					1	1
The Netherlands			4	5	1	2
Poland						
Portugal			2	2	1	1
Sweden						
Austria						
Estonia					1	1
Luxembourg						
Malta			1	1		
Slovenia						
Slovakia						

Table 10: Number of research activities per EU MS reported in the 2022 Monitoring

The numbers of wider research activities (i.e. those that do not meet all criteria for reporting) should be taken as indicative only, and are likely to change when analysed further. There are four main reasons for this:

- Underreporting: all of the trials and studies are likely to meet the criteria of more than one HCP from more than one Member State, as the identification is based on multiple Members reporting the study in their response to the Monitoring Exercise. However, the actual number of trials and studies that meet these criteria is likely to be higher, as not all Members responded to the Monitoring Exercise, and not all those who responded filled out all the information requested.
- Discrepancy with clinicaltrials.gov: in some cases, HCPs have reported participating in a trial, but do not appear on the trial listing in clinicaltrials.gov. These instances will have to be checked individually with the centres themselves.
- Sponsorship: clinical trials sponsored by the pharma industry often do not provide HCP names in the listing on clinicaltrials.gov. Therefore it is difficult to assess how many of the participating centres are in fact ERN-EuroBloodNet members. Again, this will have to be checked with the centres themselves.
- Subnetwork membership: HCPs may report participation in trials and studies that pertain to diseases within the scope of the ERN, but are not part of their officially recognised areas of expertise (for example, an HCP belonging to the oncological subnetworks being involved in a non-oncological clinical trial). Reported trials will have to be cross-referenced against subnetwork membership.

Therefore, the next stage of analysis will be to confirm the validity of the numbers obtained so far, by confirming HCP membership and participation in trials, in order to build a complete and reliable list of ERN-EuroBloodNet Members' activities, and then to promote wider adherence to reporting criteria.

## CLINICAL PRACTICE GUIDELINES AND OTHER CLINICAL DECISION MAKING TOOLS

A repository of ERN-EuroBloodNet-endorsed Clinical Practice Guidelines (CPGs) and other Clinical Decision-Making Tools (CDMTs) adopted by the ERN has been published and is available [on the website](#). The CPGs and CDMTs are searchable by subnetwork, disease group, and quality domains including scope and purpose, patients' involvement, and rigour of development. Besides the repository and search tool, the [list detailing those CPGs and CDMTs produced by the ERN](#) is also available through a dedicated section.

Monitoring Indicator	2017	2018	2019	2020	2021	2022
6.1 Number of CPGs/CDMTs adopted for diseases within the scope of the ERN (cumulative)	0	68	68	68	69	69
6.2 Number of CPGs/CDMTs produced by the ERN	0/0	0/2	0/0	0/0	1/1	2/1

Table 11: Monitoring Indicators 6.1 and 6.2, 2017-2022

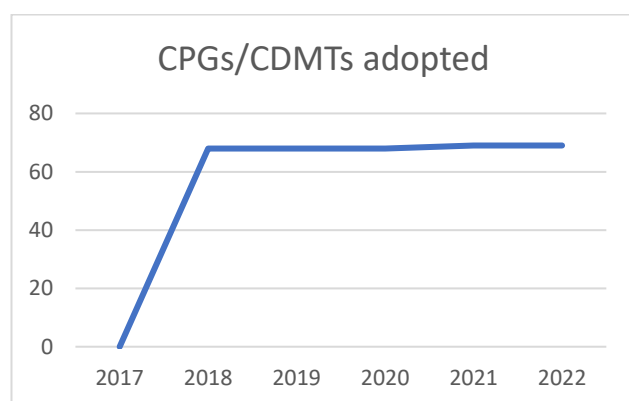


Figure 12: Number of CPGs and CDMTs adopted by ERN-EuroBloodNet 2017-2022 (cumulative)

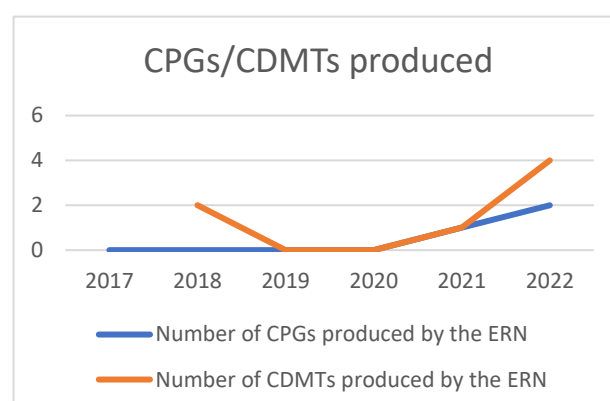


Figure 13: Number of new CPGs and CDMTs created by ERN-EuroBloodNet 2017-2022

Work remains ongoing to identify areas where guidelines and tools can be developed, adapted or updating, to continue building a comprehensive repository.

## DISSEMINATION

Dissemination activities show consistent performance, with the coordination team and members presenting the work of the ERN at different meetings and conferences, and regular visits to the [website](#). 11 presentations were made in 2022, including 2 which were identified through the data collection from Members. Efforts devoted for the promotion of the presentation of the ERN actions and logo among Members and Affiliated Partners are expected to raise these indicators in the next period.

Monitoring Indicator	2017	2018	2019	2020	2021	2022
7.1 Number of presentations	10	8	27	13	12	11
7.2 Number of individual website hits	0	0	15021	87115	56842	76093

Table 12: Monitoring Indicators 7.1 and 7.2, 2017-2022

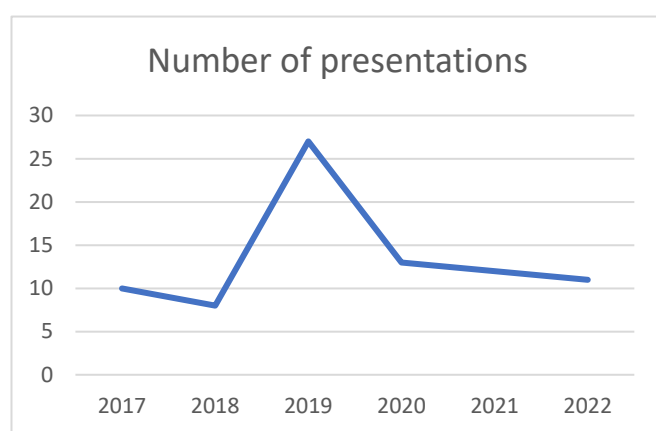


Figure 14: Number of presentations of the ERN and its activities 2017-2022

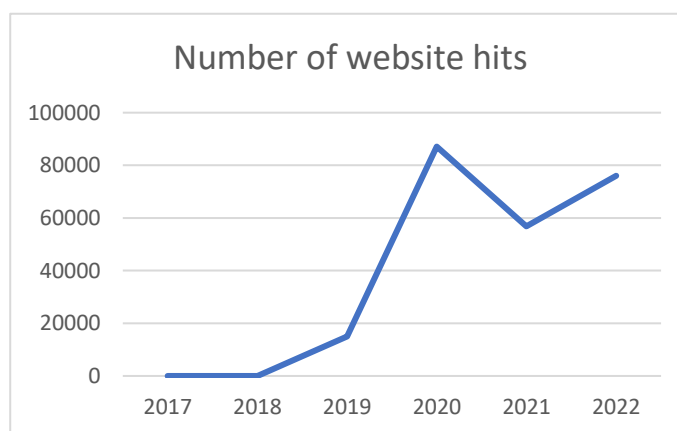


Figure 15: Number of hits on ERN-EuroBloodNet website 2017-2022

## 4. CONCLUSION

The first five years of implementation of the ERNs has been a period of growth, both in the size of the network and its activities, which will be continued and expanded further in the coming periods.

Moving forwards, all ERNs will be funded by a new grant that stipulates an expanded set of Monitoring Indicators to be reported. A strategy is being defined detailing how each indicator will be collected and the data exploited to provide insights and guide decision-making and resource allocation for future ERN activities.

Work will continue to refine and expand the information already gathered in the 8th Monitoring Exercise, in order to create an accurate database of activities within the ERN and to support active members in ensuring that activities are eligible to be reported.

Efforts will be made to engage non-responders in future exercises, and it is hoped that the new centralised Monitoring Platform under development by DG Sante will help make the process smoother and more accessible to more members.



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



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