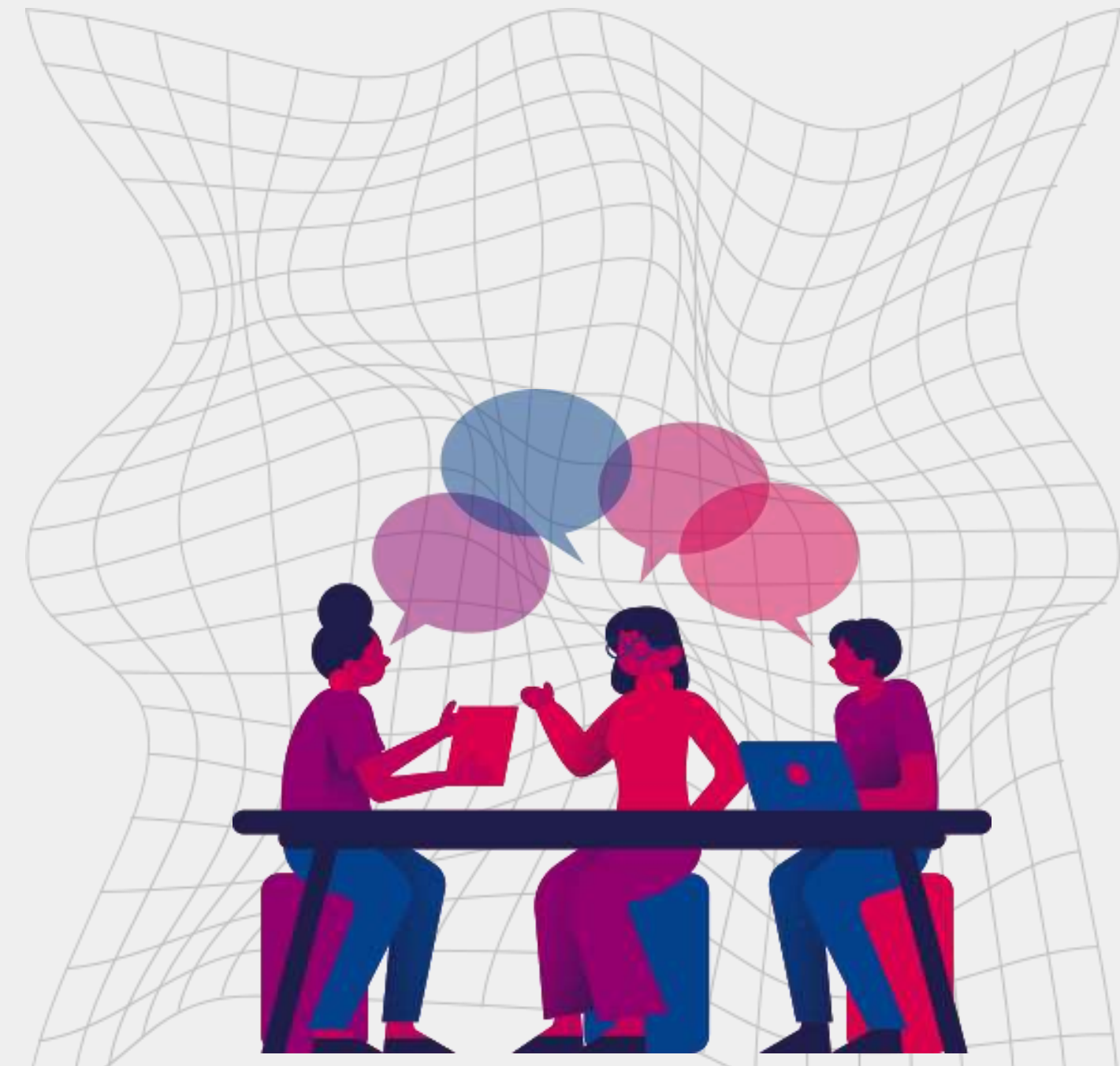


# ERN-EuroBloodNet Board of Network Meeting 2025

Scan the full **agenda**:

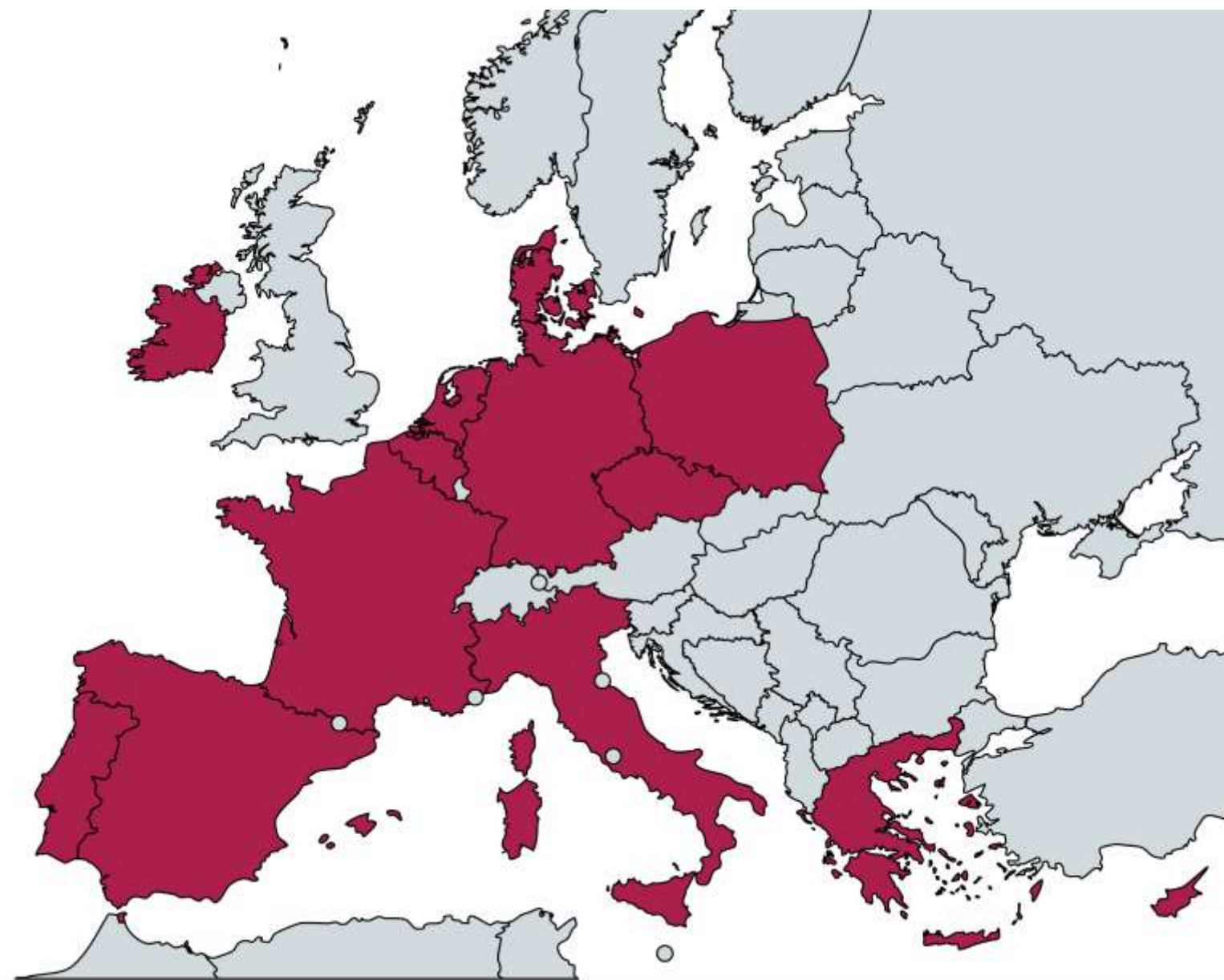
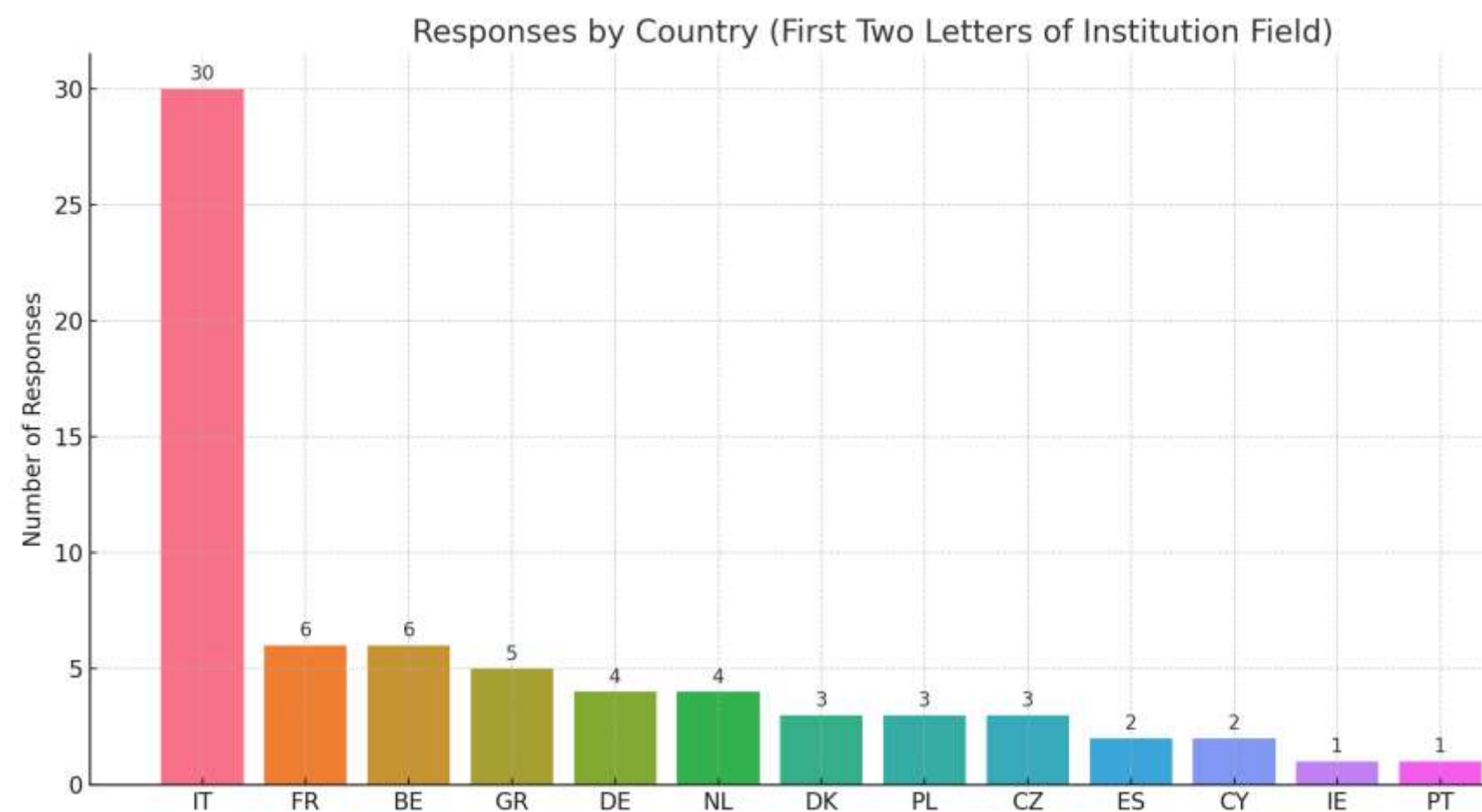


## ERN-EuroBloodNet and ENROL Registry

Boosting data driven research and innovative therapies & fostering best practices and access to highly specialized care

Today we are

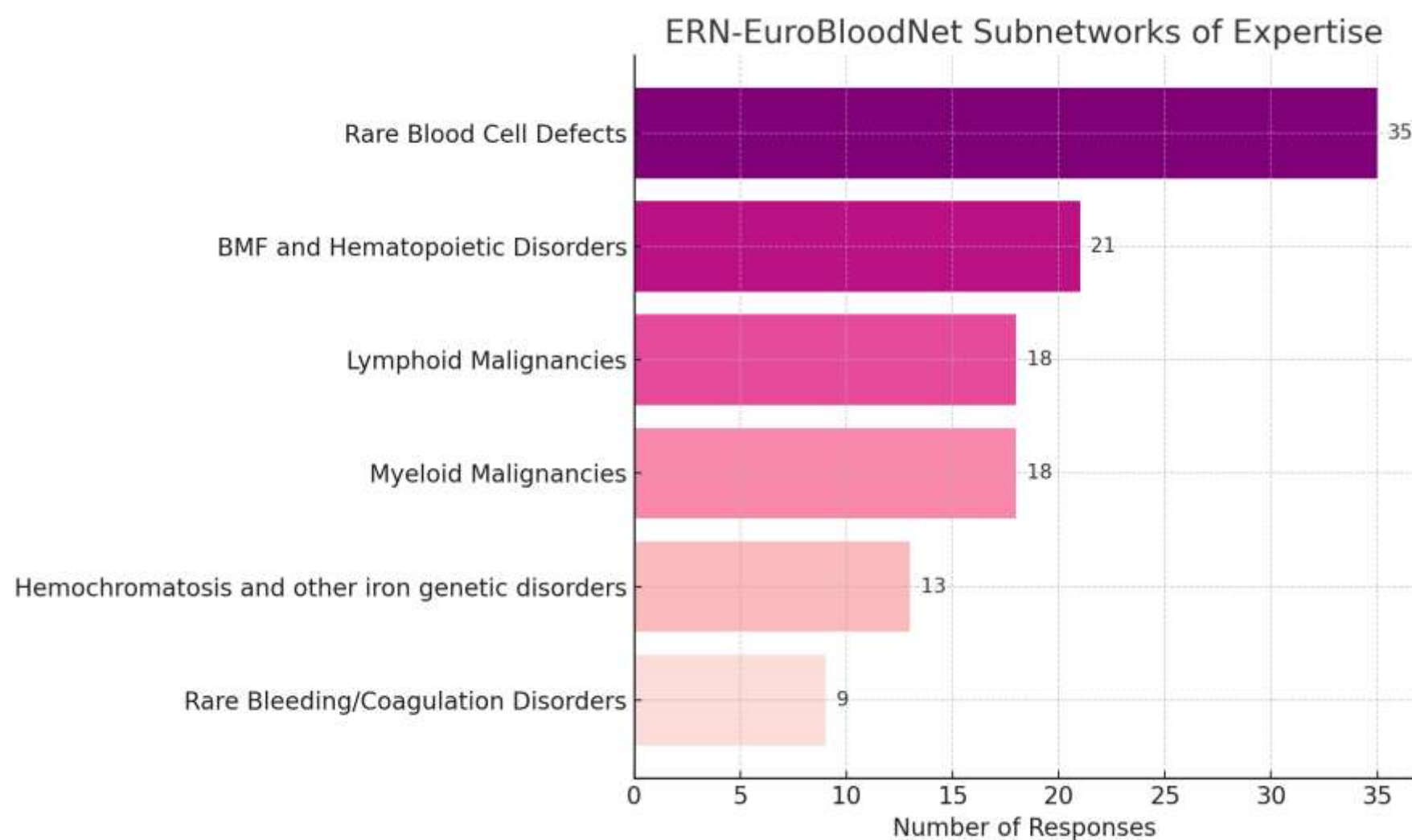
- 77 Members, APs or patients representatives
- from 53 ERN-EuroBloodNet Healthcare providers
- and 13 EU Member States





Boosting data driven research and innovative therapies & fostering best practices and access to highly specialized care

## SUBNETWORKS OF EXPERTISE



## ROLES OF PARTICIPANTS

- 41% HCP representatives
- 20% HCP representative's substitutes
- 28% Members of the HCP multidisciplinary team
- 7% Patients representatives
- 4% Other

A stylized map of Europe is shown in the background, rendered with a dotted pattern. The map is colored in shades of blue and purple, with a gradient that transitions from a darker blue on the left to a lighter purple on the right. The text is centered over the map.

# **ERN-EuroBloodNet results from Monitoring Exercise**

**Reporting year 2024**



90

Members from  
18 Member States



7

Affiliated Partners  
from  
6 Member States



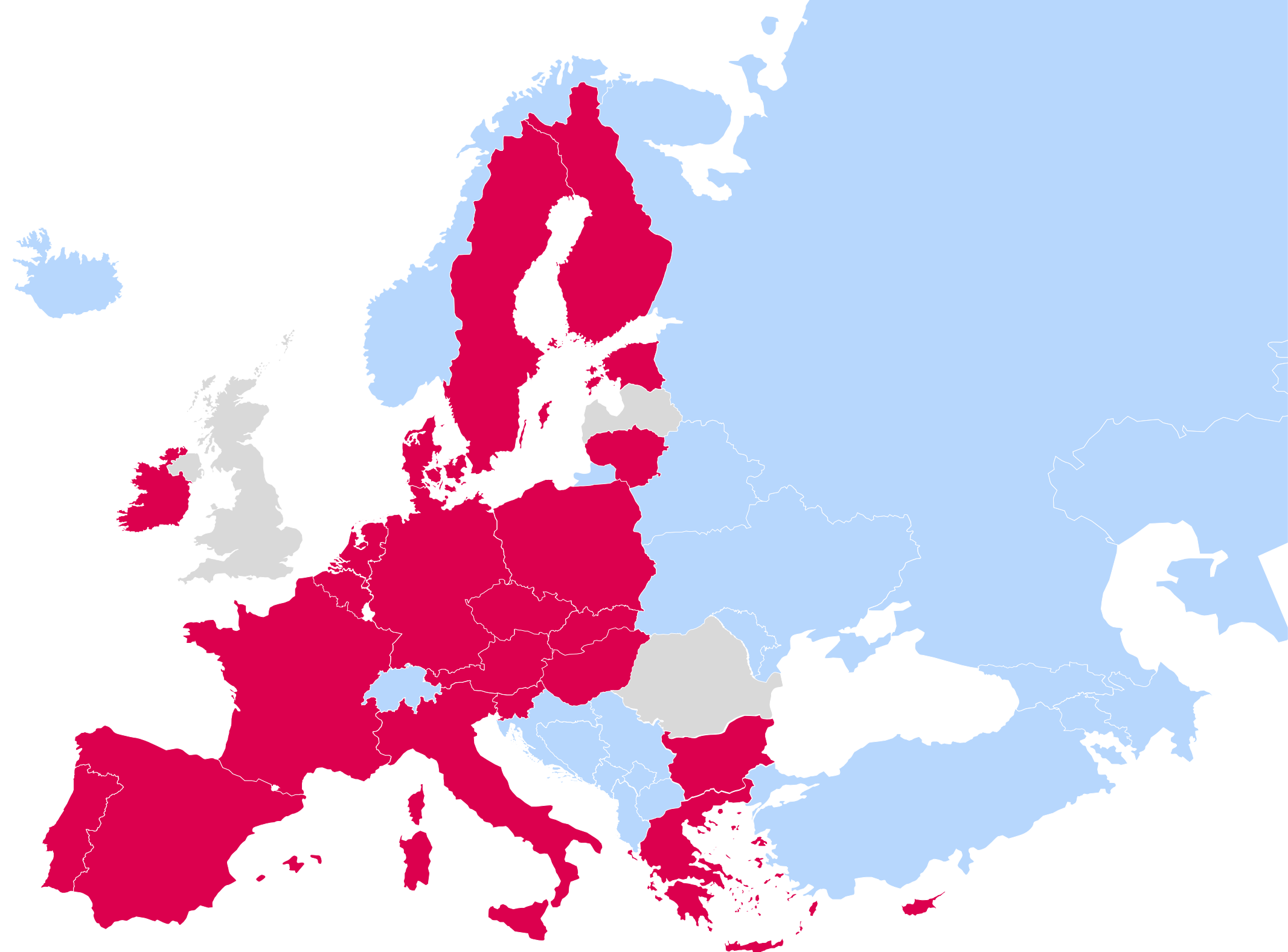
53

Patient Organizations  
involved



24176

New patients





# Education



## Non-accredited educational activities

**68**

### Non-accredited educational activities

6 Onsite trainings, 4 Online trainings,  
14 Webinars, 48 Videos,

**564**

### **Trainees who completed the training**

from 4 Onsite trainings, 2 Online  
trainings and 14 Webinars

**43**

### **Countries of origin of trainees**



## Accredited educational activities

**99**

### Accredited educational activities

4 Onsite trainings, 5 Webinars, 1  
Preceptorship,

**2061**

### **Trainees who completed the training**

from 1 Onsite trainings, 2 Online  
trainings and 4 Webinars

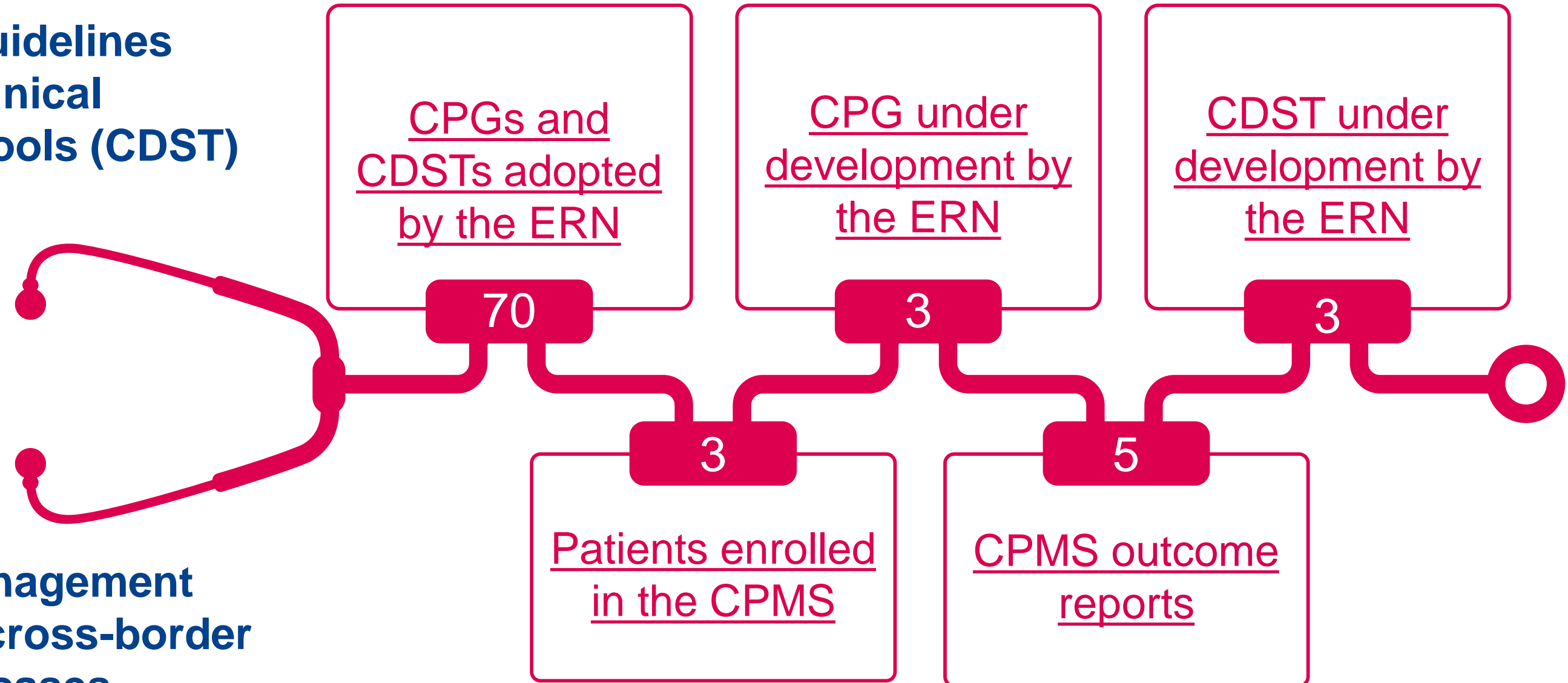
**83**

### **Countries of origin of trainees**



# Sharing of knowledge and expertise

**Clinical Practice Guidelines (CPG) and other Clinical Decision Support tools (CDST)**



**Clinical Patients Management System (CPMS) for cross-border sharing of complex cases**





# Research



**233**

## Clinical Trials

Involving at least 2 Members from 2 Member States  
1 acknowledging the ERN in clinicaltrials.gov



**4686**

## Patients with legal basis

To be uploaded to ENROL registry after signature of Data Transfer Agreement



**9**

## Peer Reviewed publications

Involving at least 2 Members from 2 Member States  
& acknowledging the ERN

**8**

## Observational studies

Involving at least 2 Members from 2 Member States  
& acknowledging the ERN in clinicaltrials.gov

**43.82%**

## of Healthcare Providers using ORPHAcodes

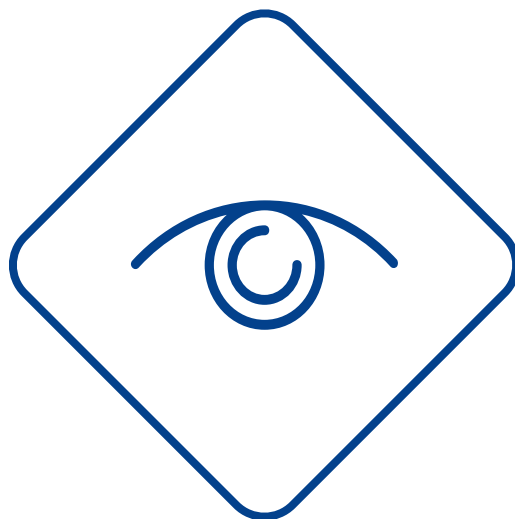




# Dissemination



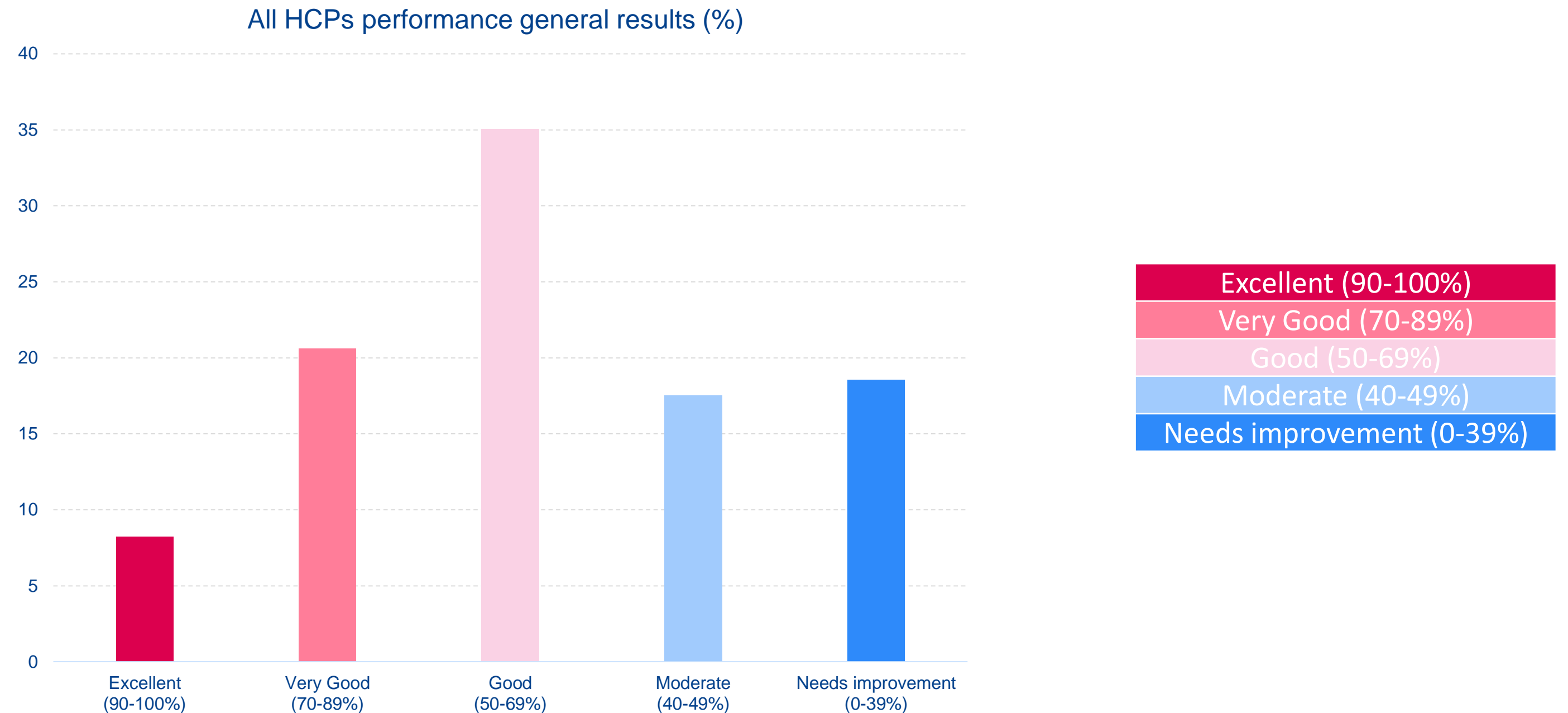
- 17** Congresses/conferences/meetings at which the ERN activities and results were presented
- 57** Presentations acknowledging ERN in 17 congresses



- 13485** New visitors to the ERN-EuroBloodNet website
- 2786** Returning visitors
- 493** Relevant documents downloaded
- 4** Dissemination webinars
- 146** Attendees to dissemination webinars



# HCPs Performance System



Based on:

- **40% - REDCap** Continuous monitoring on member activities.
  - ✓ Reporting all **member's coordinated activities**
  - ✓ Monitoring criteria **fulfilling activities**
- **60% - Participation to the ERN-EuroBloodNet coordinated activities** (Education, Clinical Trials, Observational studies, Publications and Communications, CPGs/CDMT, Presence in ERN-EuroBloodNet annual meetings).



# THANK YOU FOR YOUR COLLABORATION!

There are simple ways you can improve your score:

- ✓ **Include the ERN logo and acknowledgement** in all the activities coordinated by your HCP.

Find the ERN logo & acknowledgement in our website!

- 💬 **Complete the REDCap monitoring survey** with all the relevant activities coordinated by your HCP.

In order for the activities reported to be eligible, it is very important to complete the REDCap survey, **filling all the required information to be checked against eligibility criteria.**

- 📈 **Participate in ERN coordinated activities** like Education, Clinical Trials, Observational studies, Publications, Communications, mapping exercises and development of CPGs/CDMT.



# ERN-EuroBloodNet actions

(Not presented in today's meeting)





# Education Healthcare Professionals



Webinars for Health Professionals

## ERN-EuroBloodNet Preceptorships in Aplastic Anemia



**Coordination**  
**Prof. Carlo**  
**Dufour**

Preceptorship 1 - Aplastic Anemia in children and adolescents at the IRCCS Istituto Giannina Gaslini, Genoa, Italy.



**Coordination**  
**Prof. Régis Peffault de**  
**la Tour**

Preceptorship 2 - Acquired and Inherited Aplastic Anemia in pediatric and adult at the Assistance Publique Hôpitaux de Paris, Hôpital Saint Louis, Paris



**Coordination**  
**Prof. Jens**  
**Panse**

Preceptorship 3 - Bone marrow failure syndromes (BMFS) with a focus on aplastic anemia in adults and pediatrics at the University Hospital RWTH Aachen



- 3 webinars in collaboration with ISLH on Rare constitutional coagulation factor bleeding disorders
- Thursday Webinar: 15 webinars held + 4 upcoming
- 1 Topic on Focus on Constitutional Thrombocytopenia (15 webinars)



# EHA & ERN-EuroBloodNet Spotlight on Rare Hematological Diseases



**2022**

*Castleman Disease*

Prof Eric Oksenhendler France

Prof Kai Hübel Germany

Prof Simone Ferrero Italy

Mark Bower United Kingdom

David Boutboul France

Elena Sabatini Italy

>100 live participants

**2024**

*Hypereosinophilic Syndrome*

Prof Massimo Breccia Italy

Prof Florence Roufosse Belgium

> 300 live participants

**2025**

*BMF Syndromes*

**Prof. Régis Peffault de Latour,**  
France

**Prof Achille Iolascon,** Italy

**Prof Carlo Dufour,** Italy

**Prof Thierry Leblanc,** France

**Prof Lidye Da Costa,** France

**Prof Prof. Roberta Russo,** Italy

**Prof. Kathleen Freson,** Belgium

**Dr. Erika Massaccesi,** Italy

> 125 live participants



## New strategy for patients Education

- **Integrate Education with Research** : Equip patients with evidence-based information, the latest research findings, and cutting-edge tools to support informed decision-making and enhance their care experience.



# ASCAT

Trainings for SCD patients at ASCAT



- **ENROL webinars**
  - 3 webinars & 3 videos
- **16 videos on ENROL Registries and PROMs available in 8 languages**



- **Genomed4all 1st wave**
  - 4 webinars & 4 video
- **Genomed4all 2nd wave**
  - 6 webinars & 6 videos



7 webinars focusing Gene Therapy for SCD patient



How to read a scientific paper in Hemoglobinopathies



Work in progress



European  
Reference  
Network

Hematological  
Diseases (ERN EuroBloodNet)



Funded by  
the European Union



# Patients Actions in collaboration with International stakeholders

## Best Practices – CDSTs for patients



- Developpment of Patient Journey in vWD
- Developpment of Patient Version of Guidelines in Burkitt Lymphoma

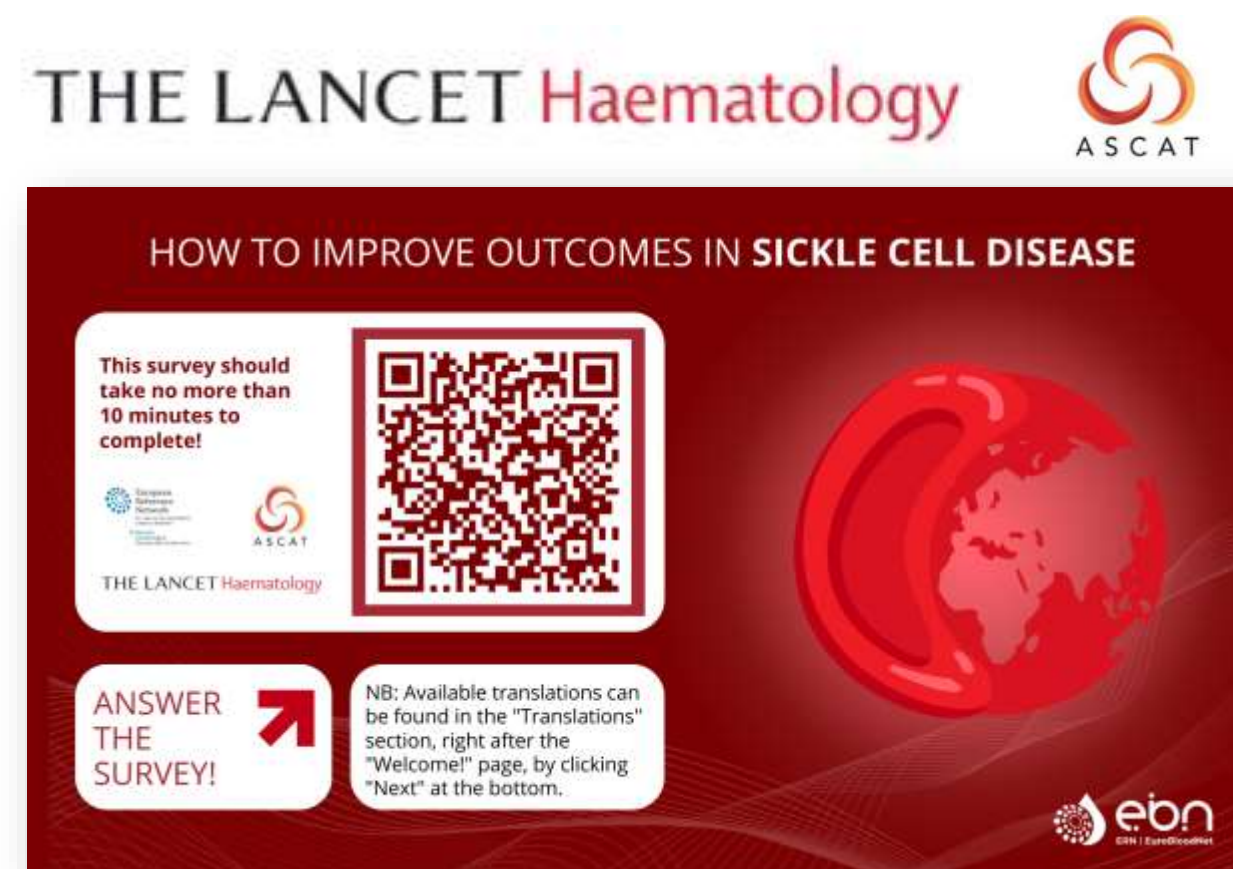


- Developpment of the Charter for optimal care transition between paediatric and adult care in sickle cell diseas



## Shaping Patient Driven Global strategy in Public Health

- Global survey assessing the perspectives of people living with SCD on how to improve outcomes in SCD







# ERN-EuroBloodNet Board of Network meeting

SESSION 1: ERN-EuroBloodNet Clinical and Data driven research - 13:15 to 14:30 CEST



**"ERN-EuroBloodNet sponsored clinical trials"**. Pierre Fenaux (AP-HP – Hôpital Saint Louis) & Eduard van Beers (University Medical Center Utrecht)



**"Role of ERN Registries in advance research in hematology"**. Sara Reidel (Vall d'Hebron University Hospital / Vall d'Hebron Research Institute)



**"GenoMed4All & SYNTHEMA AI Federated Platforms in hematology"**. Federico Álvarez (Universidad Politécnica de Madrid)



**"AI Federated platform in oncology"** Matteo Della Porta (IRCCS Clinical Institute Humanitas di Rozzano)



**"AI Federated platform in anemia"**. María del Mar Mañú Pereira (Vall d'Hebron University Hospital/ Vall d'Hebron Research Institute, Barcelona)



**"Radiomics in Sickle Cell Disease"**. Raffaella Colombatti (Azienda Ospedale – Università Padova)





# ERN-EuroBloodNet Board of Network meeting

SESSION 2: Clinical Practice Guidelines (CPGs) & Clinical Decision Support Tools (CDSTs) - 14:45 to 15:35 CEST



**"ERN-EuroBloodNet Repository of CPGs/CDSTs "**. Luca Malcovati (Foundation IRCCS Polyclinic San Matteo, Pavia)



**"Diagnosis and treatment of Burkitt lymphoma in adults: clinical practice guidelines from ERN-EuroBloodNet"**. Vincent Ribrag (Gustave Roussy, Paris)



**"ERN-EuroBloodNet Recommendations on Sickle Cell Disease."** Béatrice Gulbis (H.U.B. Hôpital Erasme – ULB, Brussels)



**"EHA/ERN-EuroBloodNet Recommendations on Rare Hemolytic Anaemia"** Richard van Wijk (University Medical Center Utrecht)



**"Clinical practice guidelines on Vexas Syndrome endorsed by ERN-Eurobloodnet"**. Pierre Fenaux (AP-HP – Hôpital Saint Louis)



**"Designing Patient-Centered Care: Patient Journeys from Educational Programs and Patient Versions of Guidelines. Pilot of von Willebrand Disease and Burkitt Lymphoma"**. Mariangela Pellegrini (AP-HP – Hôpital Saint Louis)