

ERN-EuroBloodNet

Dissemination Pills

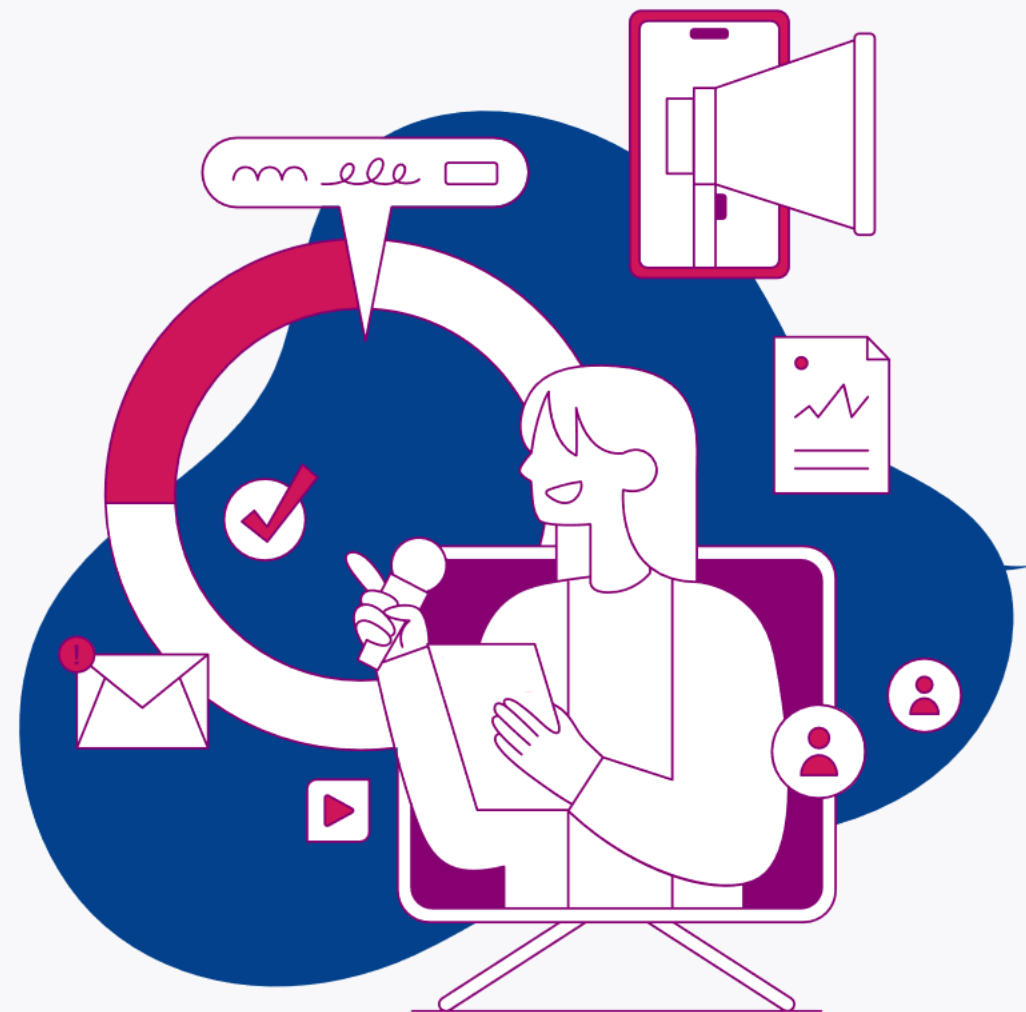
**ERN-EuroBloodNet European mapping on
Arterial Thrombosis and Venous Thrombosis in
Pediatric patients**

SPEAKER: Rubén Berrueco

Sant Joan de Déu Hospital



21st of November 2024





European Mapping venous and arterial thrombosis in children

First meeting with EBN

- **Rare disease (not recognize)**
- Many challenges including:
 - *No specific training during residence / pediatric hemato-oncology fellowships*
 - *Poor **funding** as pediatric thrombosis is not considered a rare disease*
 - *This field is not usually considered in general hematology congresses.*



European Mapping venous and arterial thrombosis in children

Mapping



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#ERNcare4Ua

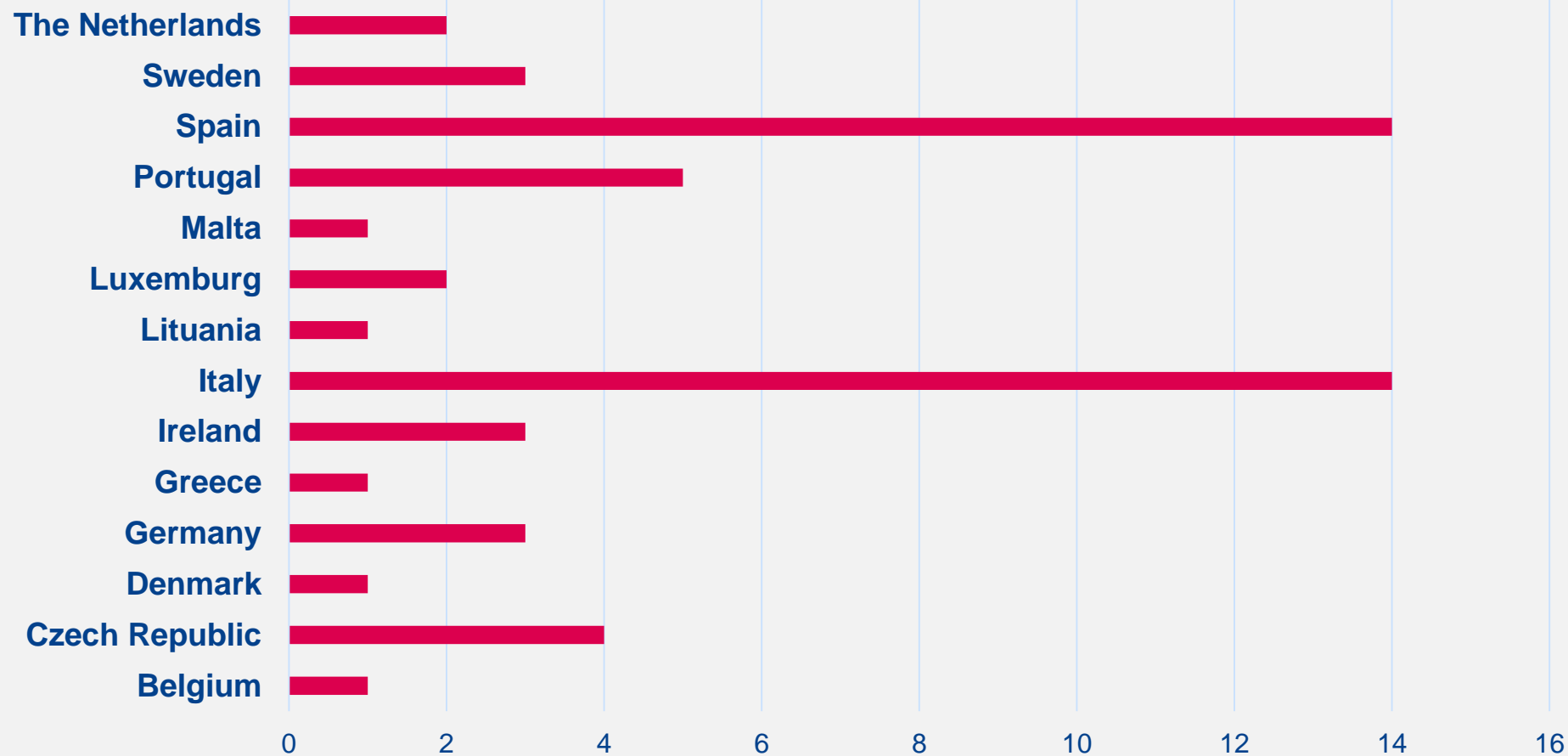
News

ERN-EuroBloodNet European Mapping for management of Venous Thrombosis and Arterial Thrombosis in Pediatric Patients – DEADLINE EXTENDED until 20th of October!

- **55 responses from 45 centers in 12 EU countries**
- **These centers treated:**
 - Venous thrombosis: 45 (all of them)
 - Arterial thrombosis: 36



European Mapping venous and arterial thrombosis in children





EHA2024
JUNE 13 - 16 | MADRID

ERN-EuroBloodNet European mapping for management of Venous thrombosis and Arterial thrombosis in pediatric patients: the first European pediatric thrombosis Working group

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1 Vall d'Hebron University Hospital / Vall d'Hebron Research Institute, Barcelona, Spain, 2 Erasmus MC Sophia Children's Hospital, Rotterdam, The Netherlands, 3 Hospital de Sant Joan de Déu, Barcelona, Spain

INTRODUCTION

Thromboembolic events (TE) are increasingly recognized in children. Compared to adults, pediatric TE are rare and differ in epidemiology. Current guidelines are based on low evidence data and information extrapolated from adult studies. Thus, international collaboration is essential to enable high-quality research to improve the evidence for its management.

AIM

Assess the current care of TE across Europe and set up a working group in the context of the European Reference Network on Rare Hematological Diseases (ERN-EuroBloodNet).

METHODS

A European Mapping exercise was defined by two ERN-EuroBloodNet experts and conducted through "Google Surveys".

Survey was divided in two sections:
a) Venous Thrombosis (VT)
b) Arterial Thrombosis (AT)

Including questions on:

- Epidemiology
- Use of guidelines
- Treatment
- Participation in clinical trials
- Participation in registries (e.g. Pediatric Thrombosis registry (IPTN))

Answers were collected from June 2023 to January 2024 anonymously, but participants had the chance to provide their contact details.

RESULTS

A total of 57 responses were gathered from 45 centers in 12 EU countries (Fig. 1). Treating VT=45, treating AT=36. Of them, 47% were ERN-EuroBloodNet members.

Number of patients in follow up per year was highly superior for VT, where 56% responders followed >30 patients, in comparison to 93% following 0-10 patients with AT (Fig. 2)

Most of the participants follow the international guidelines for thrombosis. Parenteral anticoagulation is the most common strategy for VT, followed by oral anticoagulation with direct oral anticoagulants (DOACs). Regarding AT, anticoagulation was the most used strategy (Fig. 3)

Thrombolysis and thrombectomy are available options in most of the centers (both n=31; none of them n=8; thrombolysis n=4; thrombectomy n=2). Thrombophilia testing is always done after VT or AT in 18 centers. The other centers make a tailored approach.

Clinical trial participation for the development of new anticoagulant treatments for VT was higher (44%) compared to AT (31%). Although only 24% of responders belonged to International Paediatric Thrombosis Network (IPTN), all the respondents are interested in participating in a European registry, and 96% in the future ERN-EuroBloodNet working group.

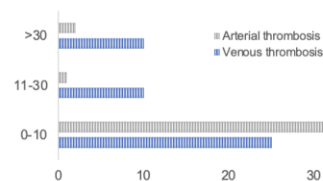


Fig 2. Number of centers concentrating 0-10, 11-30 or >30 patients in follow up per year

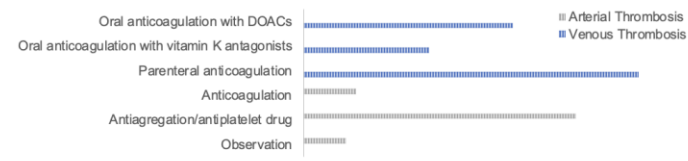


Fig 3. Percentage (%) of centers general treatment approach



Fig 1. Number of centers and countries contributing to the EU Mapping

CONCLUSIONS

This survey reflects the state of the art of pediatric thrombosis care throughout Europe, highlighting the participation from 12 countries.

TE incidence appeared low, especially for AT, where only 4% of hospitals follows more than 30 patients/year. Most recent guidelines are generally followed. More than 50% of the patients are treated with heparins followed by DOACs. The high thrombolysis and thrombectomy availability is probably related to the fact that respondents work in pediatric reference centers. Enrolment of patients in clinical trials seems to be very low.

Despite the low occurrence of TE, all participants have shown enthusiasm for establishing the ERN-EuroBloodNet Pediatric Thrombosis Working Group to enhance collaborations on:

- Development of Recommendations for care (mainly focused on prophylaxis) and the "European Principles of Care for Pediatric Thrombosis": EPIC-PeT
- Periodical clinical sessions for cross border sharing of complex cases through the [Clinical Patients Management System](#)
- Reinforce epidemiological surveillance in collaboration with IPTN and through the contribution to the [European Rare Blood Disorders Platform \(ENROL\)](#) as the ERN-EuroBloodNet central registry for rare hematological diseases.

CONTACT

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ACKNOWLEDGEMENT



This project is carried out within the framework of European Reference Network on Rare Haematological Diseases (ERN-EuroBloodNet)-Project ID No 101157011. ERN-EuroBloodNet is partly co-funded by the European Union within the framework of the Fourth EU Health Programme. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or European Health and Digital Executive Agency (HaDEA). Neither the European Union nor the granting authority can be held responsible for them.





European Mapping form venous and arterial thrombosis in children

Orpha-codes

Entities with ORPHA-CODE

Disease	ORPHA-CODE
Cerebral sinovenous thrombosis	329217
Portal vein thrombosis	854
Isolated mesenteric vein thrombosis	583861
Isolated splenic vein thrombosis	583861
Budd-Chiari syndrome	131
Thoracic outlet syndrome	357131
Heparin induced thrombocytopenia	3325

Entities without ORPHA-CODE

Disease	ORPHA-CODE
Pediatric deep vein thrombosis (including DVT, PE)*	-
Pediatric cardiac thrombosis	-
Neonatal renal vein thrombosis	-
May-Turner syndrome	-
Pediatric arterial thrombosis	-



European Mapping form venous and arterial thrombosis in children

Orpha-codes

Entities with ORPHA-CODE

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Budd-Chiari syndrome	131
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Entities without ORPHA-CODE

Disease	ORPHA-CODE
Pediatric deep vein thrombosis (including DVT, PE)*	-
Pediatric cardiac thrombosis	-
Neonatal renal vein thrombosis	664912
May-Turner syndrome	675404
Pediatric arterial thrombosis	-



ERN-EuroBloodNet – PeT WG

Pediatric Thrombosis Working Group



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Dra. Heleen van Ommen

Head of Pediatric Hematology Department
Erasmus MC Sophia Children's Hospital, Rotterdam.



Aims for EBN - PeT WG

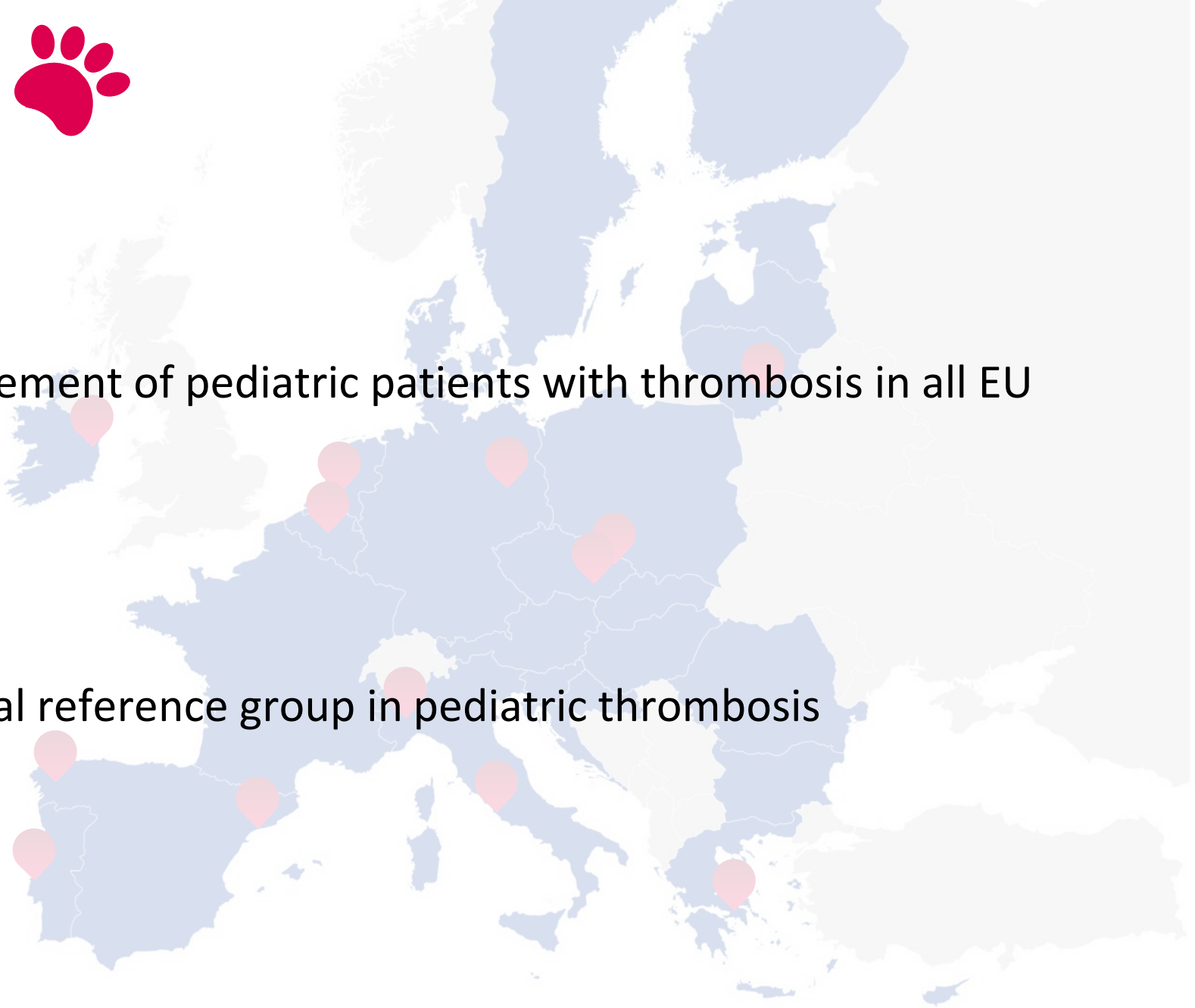


Mission

- To ensure the best management of pediatric patients with thrombosis in all EU countries.

Vision

- To become an international reference group in pediatric thrombosis



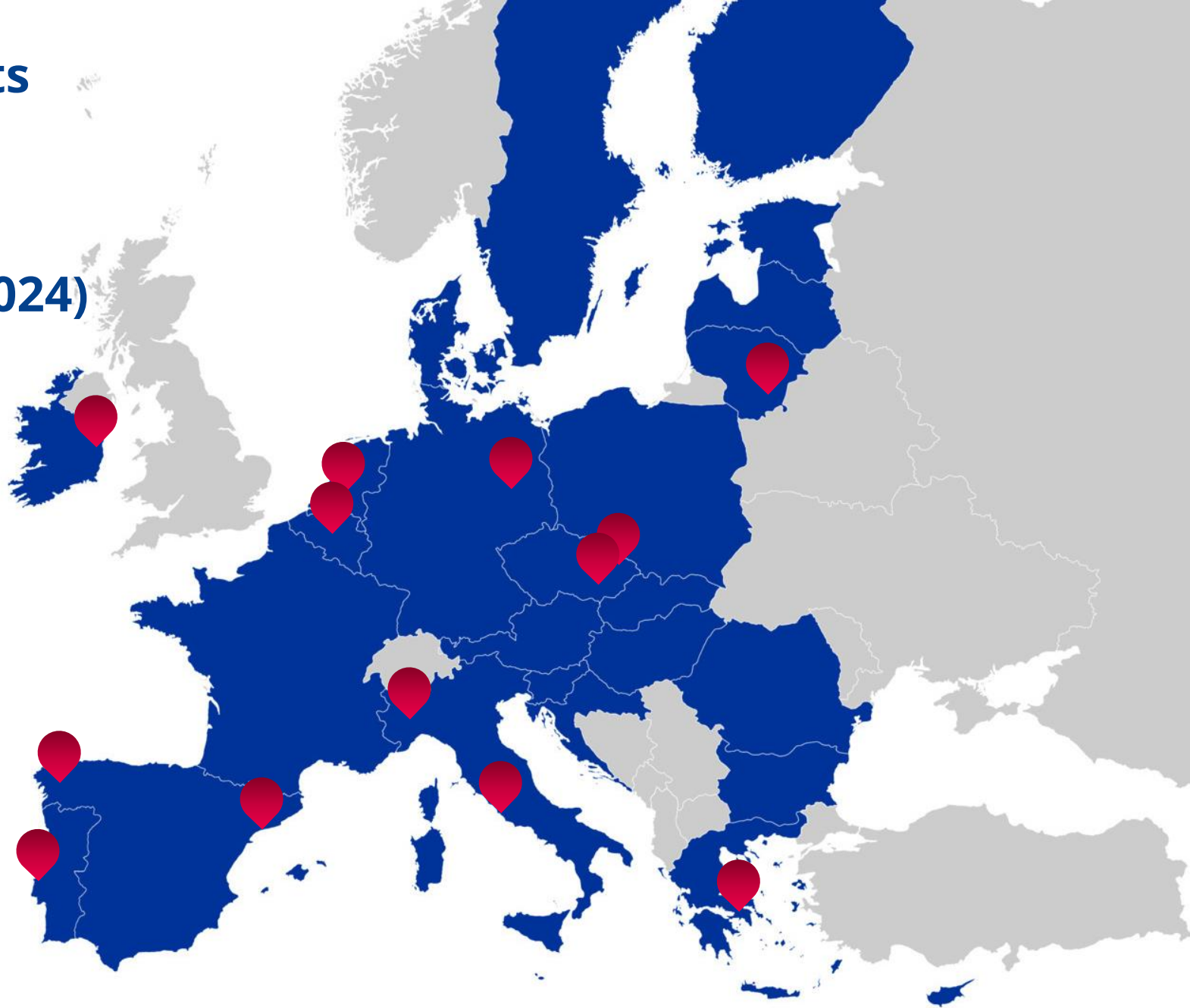
Core group participants



EBN - PeT WG



1st meeting (7th May 2024)





Name	City / Country	Hospital	e-mail
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Core group EBN-PeT WG



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Chat

People

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Raise

React

View

Notes










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Mic

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 <div>KΑΛΤΣΙΑΣ ΑΘΑΝΑΣΙΟΣ</div>	 <div>Veerle Labarque (Guest)</div>	 <div>Tomas Kuhn (Host) (Guest)</div>	<div><div>BN</div><div>Beatrice Nolan (Guest)</div><div><div>1</div><div>G</div></div><div>Giovanni (Guest)</div></div>
 <div>Raquel Maia (Guest)</div>	 <div>Heleen van Ommen</div>	 <div>Pavel Mazánek (Guest)</div>	
 <div>Gutierrez Valle, Victoria</div>	 <div>Holzhauser, Susanne</div>	 <div>Sonata Šaulytė Trakymienė</div>	



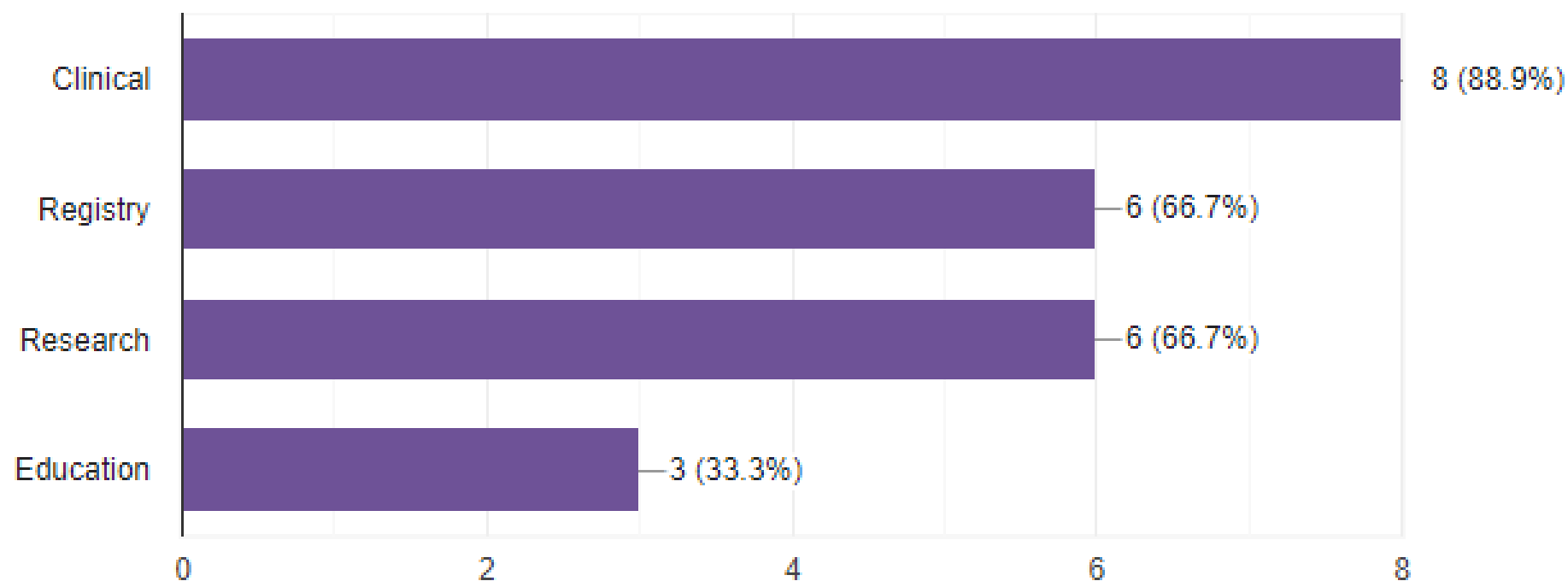
Aims for EBN-PeT WG: pre-work



What are the most relevant area/s to work within the working group in your opinion?

 Copy

9 responses



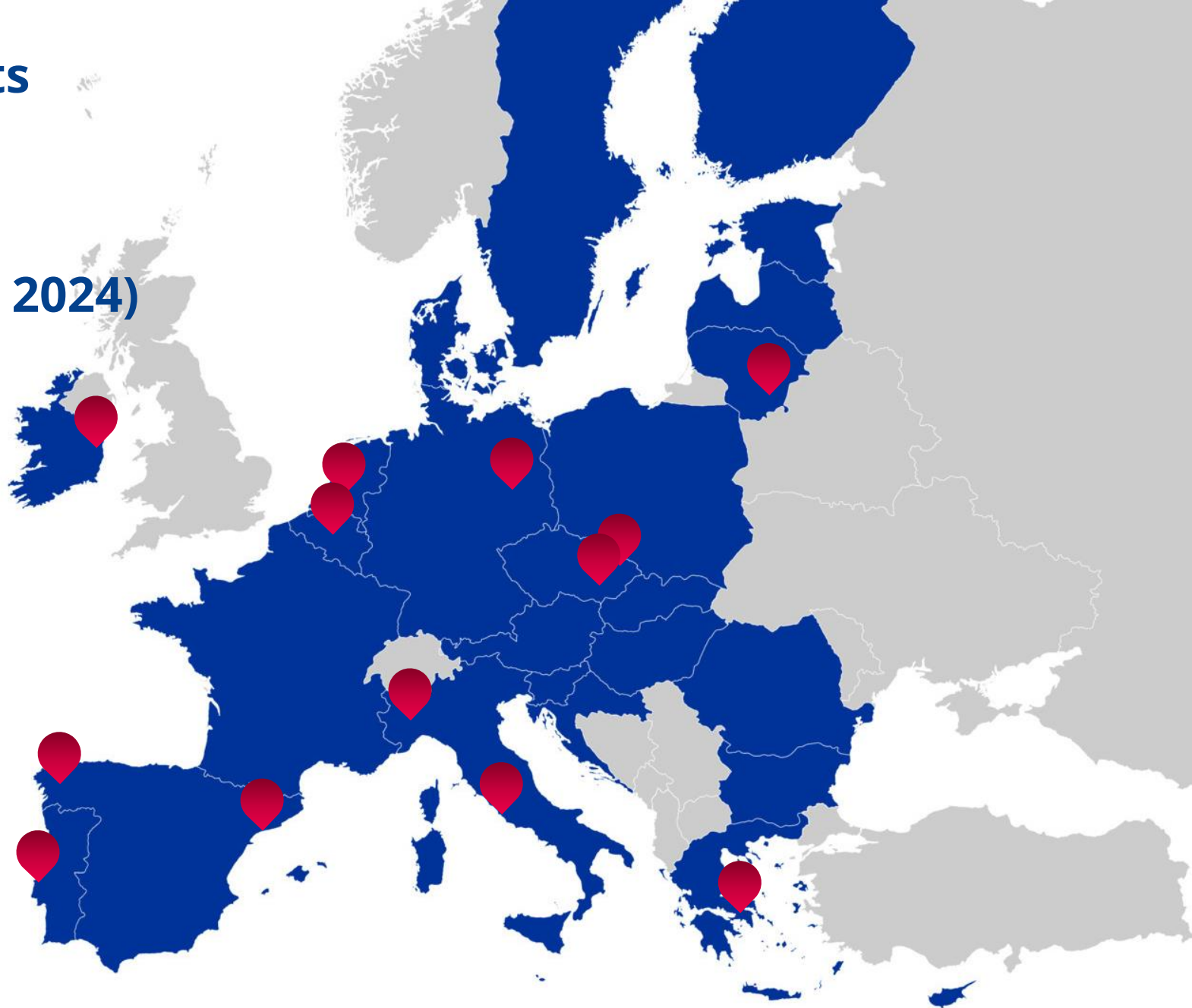
Core group participants



EBN - PeT WG



2nd meeting (24th Sept 2024)



Aims for EBN-PeT WG



What to do?



Telemedicine

- Periodical **clinical sessions** for sharing difficult cases using Clinical Patient Management System (ideally CPMS 2.0)



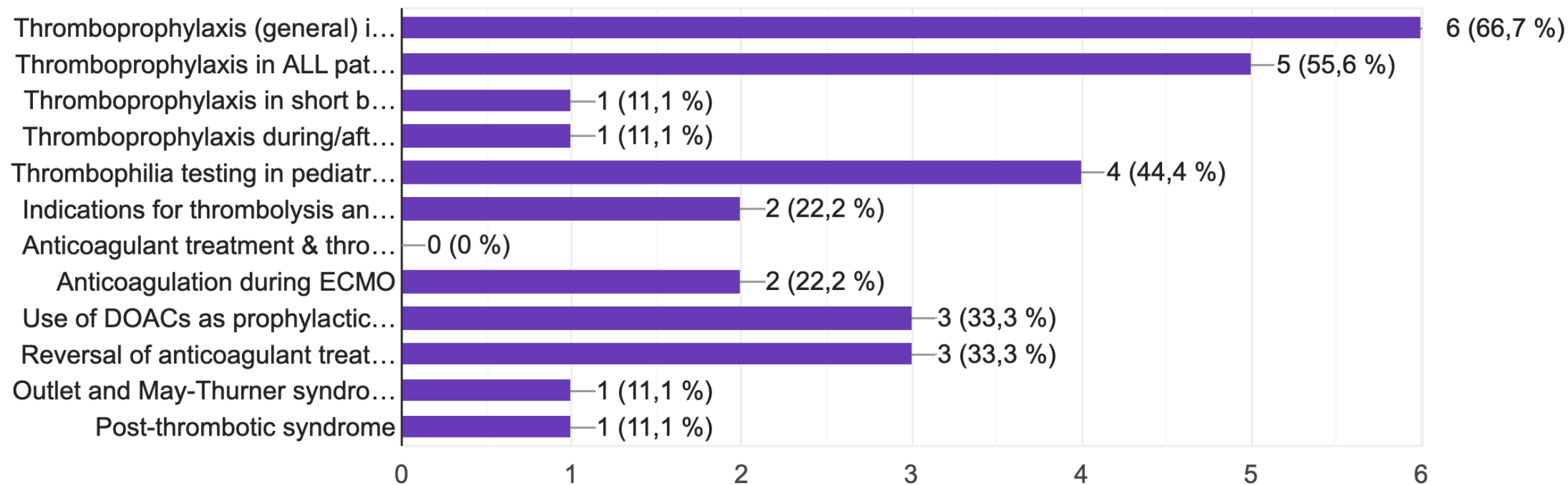
Best practices

- Recommendations for care (mainly **focused on prophylaxis**, which is the identified gap by the core group): “Learning from the case”
- Promoting the “European Principles of Care for Pediatric Thrombosis”: **EPiC-PeT**



Learning from the case topics (please, vote 2-3 options)

9 respuestas

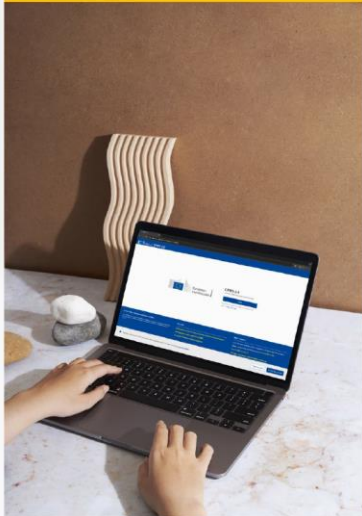




Telemedicine

- Periodical **clinical sessions** for sharing difficult cases using Clinical Patient Management System (ideally CPMS 2.0)

CPMS 2.0 Quick Start Guide for Clinicians



This document aims at assisting you in your first contacts with the CPMS 2.0 IT platform. A training environment has been set up to enable you to explore all the system's features without using real patient data.

When using the real system (with real patients), please make sure you always follow the data privacy procedures of your hospital.

You can access the application for testing purposes by clicking on the following link:
<https://cpms2-acceptance.ern-net.eu/>

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**Thank
You!**

