



EUROPEAN REFERENCE NETWORKS Monitoring report 2025



European
Reference
Networks

EUROPEAN REFERENCE NETWORKS

Monitoring report 2025



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PDF ISBN 978-92-68-33446-1 doi:10.2875/4744182 EW-01-25-122-EN-N

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Introduction

Rare diseases are a significant public health issue in Europe, affecting an estimated 30 million people. These diseases are often chronic, debilitating, sometimes life-threatening, and can have a profound impact on patients' quality of life. This is why the Commission has been active in addressing rare diseases for more than 20 years now.

One of the flagship activities of the Commission in the field of rare diseases is the European Reference Networks (ERNs) initiative. Created under the Directive on patients' rights in cross-border healthcare ⁽¹⁾, the ERNs were launched in March 2017. The ERNs are cross-border networks that bring together European hospital centres of expertise to tackle rare, low prevalence and complex diseases and conditions requiring highly specialised healthcare. The ERNs enable specialists in Europe to discuss cases of patients affected by rare, low-prevalence and complex diseases, providing advice on the most appropriate diagnosis and the best treatment available. Having increased in scope and size since their establishment in 2017, the ERNs now comprise 24 Networks, including 1,606 clinical centres belonging to 375 hospitals across 27 EU Member States and Norway.

DG SANTE has taken the initiative to produce this report in order to showcase the growth and professionalization of the ERNs since their inception in 2017. Moreover, the publication of this data serves to provide an insight into the different areas of work of the ERNs, their reach, impact and added value for patients leaving with rare diseases and their families. By publishing this report, DG SANTE aims to increase awareness and visibility of the work of these 24 Networks, which are a flagship activity of the Commission in the field of rare diseases.

This is the first time that a monitoring report on the ERNs activity is produced for publication. The report takes into account the feedback received from the ERN Coordinators. The report is available on the Europa website: [European Reference Networks - European Commission](#).

The work of the ERNs has been organised in the ERN grants of 2023-2027 around seven core areas, listed below. This allows, among other things, consistency across the 24 ERNs in terms of structure, reporting and monitoring as well as enabling more efficient synergies and sharing of best practices. This report follows the structure of the 2023-2027 grants. The seven core areas of work are:

1. **Coordination:** general organisation and coordination of the ERNs.
2. **Dissemination:** communication and dissemination of the activities of the ERNs.

(¹) Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare

3. **Evaluation:** development of a sound evaluation methodology to capture and measure different activities of the network.
4. **Healthcare and Clinical Patient Management System (CPMS):** use of the telemedicine platform for cross-border clinical discussions.
5. **Registries:** use of registries and their expansion with respect to the EU Rare Disease Platform and under the European Health Data Space.
6. **Training and Education:** development and implementation of education and training activities on rare diseases aimed at healthcare professionals, young doctors and medical students.
7. **Clinical Practice Guidelines and other Clinical Decision Support Tools:** assessment, development, update and dissemination of Clinical Decision-making tools.

The work of the ERNs is reported to the Commission via regular data collection exercises, known as the continuous monitoring of the ERNs. The monitoring takes place in a single data collection per year, due in March, covering the period from January to December of the previous year. This monitoring is based on a set of 24 indicators which altogether cover the seven core areas of the ERN grants. The purpose of the indicators and the value of the data provided by the ERNs is pivotal: it illustrates the progress across the seven core areas of ERN work and helps to show and substantiate the added value of ERN activities and areas for improvement.

The 2025 data collection exercise focuses on these indicators, as described in the table below:

Indicator	Inclusion in the 2025 Report	Core Area of Work
1. ERN Member (HCP) Performance Indicator Score	Yes	1
2. Website traffic dataset	No	2
3. Number of downloaded documents from ERN website	Yes	3
4. Number of dissemination webinars	Yes	2
5. Number of webinars attendees	Yes	2

6. Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	Yes	4
7. Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	Yes	4
8. Active participation in the new CPMS development, testing and roll-out	Yes	4
9. Implementation of the pilot scheme for reimbursement and drafting of recommendations for improvement	No	4
10. Number of new patients (entering the registry)	Yes	5
11. Percentage of the total ERN patients that are included in the registry(ies)	Yes	5
12. Mapping of the registries/data sources in all the clinical units constituting each ERN (i.e., provide a list of the existing patient data sources in the clinical units of the ERN that are relevant for the ERN work on registries)	No	5
13. Metadata of the registries/data sources provided to the Directory of Registries and Central Metadata Repository of the Joint Research Centre	No	5
14. Design, proposition and implementation of a practical technical model to connect and make registries interoperable (using the European Rare Diseases Registry Infrastructure, tools and services)	No	5
15. Implementation of pseudonymisation, data linkage and data transfer services in line with JRC recommendation (SPIDER)	No	5
16. Mapping of the use of orphacodes in all clinical units	Yes	5
17. Number of accredited Training Courses developed by the ERNs (not congresses, conferences, events which do also carry CME credits)	Yes	6
18. Number of trainees who completed accredited Training Courses	Yes	6

19. Number of countries of origin of trainees who completed accredited Training Courses	Yes	6
20. Number of non-accredited training courses developed by the ERN	Yes	6
21. Number of trainees who completed the non-accredited training courses	Yes	6
22. Number of countries of origin of trainees who completed the non-accredited training courses	Yes	6
23. Number of Clinical Practice Guidelines developed, updated, or appraised	Partial	7
24. Number of Clinical Decision Support Tools developed, updated, or appraised	Partial	7

Six indicators (2, 9, 12, 13, 14 and 15) were not included in the 2025 data collection exercise for various technical reasons and will be included in future data collections.

Two indicators (23, 24) are partially included. The ERNs reported to DG SANTE on Clinical Practice Guidelines and Clinical Decision management tools but nuanced according to if they were adopted or written and released – this can be seen in the ERN indicator tables below.

Two indicators (6, 16) were provided directly by ERN members and Affiliated Partners. The remaining ones were provided by the ERN coordination teams.

The report is organised into two chapters: the first chapter provides an overview of all the ERNs data submitted per indicator, while the second chapter provides a country profile of each Member State and Norway including a statistical overview of the country's participation across the ERNs.

Data Limitations

There are some limitations to the data presented in this report. Firstly, the direct submission of data from members and affiliated partners does not reach 100% of submissions, as illustrated in figure 1.

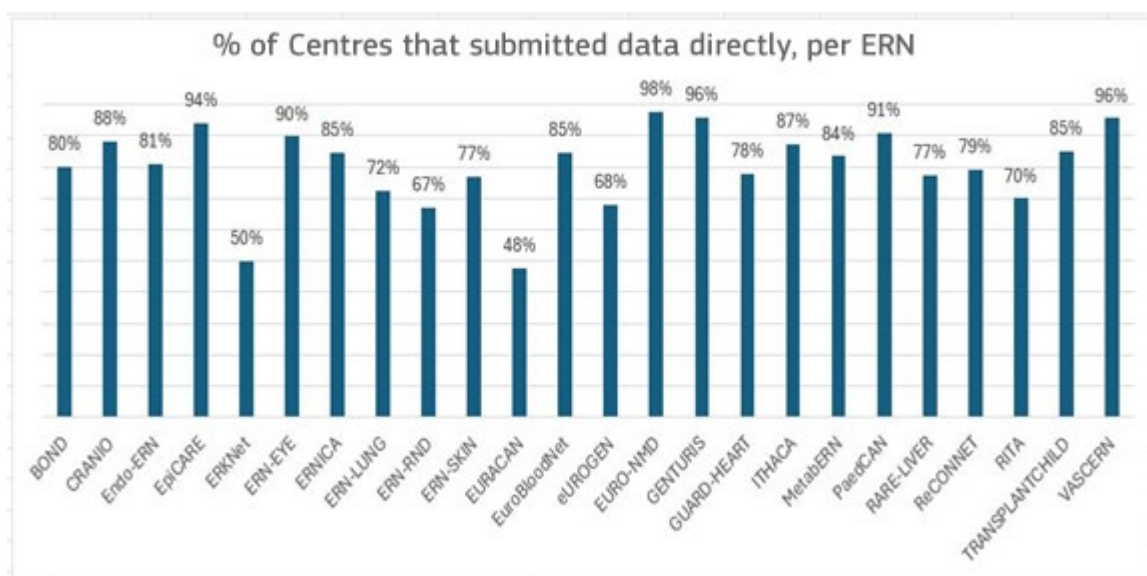


Figure 1. ERNs members and affiliated partners submission level

Secondly, for comparative purposes, this report has included data of 2023. Non-comprehensive data submission results in empty data points for certain indicators.

Thirdly, certain data may reflect different interpretations of the indicator and thus is heterogeneous across the ERNs.

Fourthly, the processing of the submitted data has not yet been fully automated and may therefore still include human errors.

Overall, the collection of data from the ERNs and the processing of this data needs further improvement going forward. The data limitations also render the analysis of the indicators challenging and therefore this was omitted in this report. Improvements going forward include automation of data processing; homogeneous interpretations of indicator definitions; inclusion of qualitative context; and comprehensive and accurate reporting from ERN members and affiliated partners.

Chapter 1

European Reference Networks



European
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Networks

This chapter provides an overview of each ERN's area of work, size of memberships and submitted data, reflecting the situation at 31/12/2024. A brief explanation of the indicators used for reporting follows:

Coordination: general organisation and coordination of the ERNs. Coordination activities are essential for the management and operational activities of the ERNs. *Indicator 1*, the Health Care Provider Performance Indicator System specifically refers to the presence or not of an ERN system to measure the contribution of each clinical centre to ERN activities.

Dissemination: communication and dissemination of the activities of the ERNs. Dissemination of the knowledge generation of the ERNs to a wide audience is integral to their work. *Indicators 3, 4 and 5* provide insight into dissemination activities like website use and webinars. *Indicator 2* was omitted from this monitoring exercise because it requires a full report on its own and it was not possible to integrate it into the current monitoring platform.

Healthcare and Clinical Patient Management System (CPMS): use of the IT telemedicine platform for cross-border clinical discussions.

The ERNs use an online IT platform, known as the Clinical Patient Management System (CPMS), to facilitate collaboration between healthcare professionals across Europe and support the diagnosis and treatment of rare, low-prevalence, and complex diseases. The CPMS was launched in 2017 and replaced in mid-December 2024 by CPMS 2.0 to address limitations encountered in the first version.

Indicator 6 provides insight into the healthcare activities and healthcare availability of members of the ERNs. This indicator provides for comparative analysis over time. For example, in 2018 data, ERNs indicated a total of 161 000 new patients, whilst 2024 data illustrate 416 000 new patients and therefore a growth of around 160% over the course of 6 years in terms of ERN network coverage of rare patient care in Europe.

Indicator 7 reflects mainly the use of the old CPMS in 2024 and 2023. It is expected that the use of CPMS 2.0 will grow in comparison to usage of the first version.

To ensure the development of the new CPMS 2.0 was fit for purpose, ERNs were invited to participate in its development, testing and roll out. *Indicator 8* measures this achievement and was computed based on the participation of each ERN in the meetings of the CPMS 2.0 Business Implementation Group. In the coming years this indicator will be phased out.

Indicator 9 was omitted from this monitoring exercise due to technical reasons in the current monitoring platform.

Registries: use of registries and their expansion with respect to the EU Rare Disease Platform and under the European Health Data Space.

The ERNs set up transnational registries to collect pseudo-anonymised data on patients with rare diseases. They are an important component of digitalised European healthcare establishing a rare disease registry ecosystem based on interoperability and FAIR ⁽²⁾ principles. They harmonise data on rare disease patients across the EU, and make data collected available to researchers, public authorities, industry and other stakeholders on different conditions to direct improvement in the medical care of patients.

Indicators 10 and 11 provide insights into the registry activity. Due to technical difficulties in the monitoring platform, *indicators 12, 13, 14 and 15* were omitted from this monitoring exercise.

Indicator 16 maps of the use of Orphacodes in all clinical units. Orphacodes are an internationally valid classification system for rare diseases that serves to identify rare disease patients. Orphacodes can make it easier to identify and diagnose a patient's disease and to improve the visibility of rare diseases in a health and research information system.

Training and Education: development and implementation of education and training activities aimed at healthcare professionals, young doctors and medical students.

The ERNs provide training and education for their members through webinars, conferences, clinical exchanges and endorsement/accreditation of educational activities. It serves to promote and spread more widely expert knowledge at EU level. *Indicators 17, 18, 19, 20, 21 and 22* provide insight into this area of ERN activity.

Clinical Practice Guidelines and other Clinical Decision Support Tools: assessment, development, update and dissemination of guidelines and tools.

Indicators 23 and 24 provide insights into this activity. The ERNs develop, update, and appraise Clinical Practice Guidelines and support tools, which serve to guide clinicians about the care of patients with specific conditions. They are based on the best available research evidence and practice experience.

(2) Findability, Accessibility, Interoperability, and Reusability (FAIR)

BOND

ERN BOND works on rare bone disorders. It covers skeletal dysplasias and metabolic bone-related conditions and all rare diseases affecting cartilage, bone, and dentine disease areas.

This ERN included 50 healthcare providers located in 19 countries in the EU and Norway, distributed as follows:

- 44 Full Members in 13 Member States, plus Norway
- 2 Associated National Centres in 1 Member State
- 4 National Coordination Hubs in 4 Member States

In addition, 9 European Patient Advocacy Groups (ePAGs) and other national patient organisations collaborate in the ERN activities.

KPI# BOND Indicators overview

Coordination		2023	2024
1	ERN Member (HCP – Health Care Provider) Performance Indicator System	No	Yes
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	N/A	744
4	Number of dissemination webinars	0	4
5	Number of webinars attendees	0	190
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	4253	3998
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	17	13
8	Active participation in the new CPMS development, testing and roll-out	92%	92%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	907	947
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	21.3%	24%
16	Mapping of the use of Orphacodes in all clinical units	63%	70%

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Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	12	27
18	Number of trainees who completed accredited Training Courses	700	1573
19	Number of countries of origin of trainees who completed accredited Training Courses	63	30
20	Number of non-accredited training courses developed by the ERN	15	33
21	Number of trainees who completed the non-accredited trainings	420	2185
22	Number of countries of origin of trainees who completed the non-accredited Training Courses	25	25
Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	6	5
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	0	0

CRANIO

ERN CRANIO works on rare craniofacial anomalies and ear, nose and throat disorders. It covers craniofacial anomalies, cleft lip/palate and odontological disorders, and ENT (Ear, Nose & Throat) disorders.

This ERN included 42 healthcare providers located in 21 countries in the EU and Norway, distributed as follows:

- 35 Full Members in 14 Member States, plus Norway
- 5 Associated National Centres in 4 Member States
- 2 National Coordination Hubs in 2 Member States

In addition, 9 patients' representatives and 7 supporting partners collaborate in the ERN activities.

KPI#

CRANIO Indicators overview

Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	No	Yes
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	0	0
4	Number of dissemination webinars	1	2
5	Number of webinars attendees	31	164
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	9759	9492
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	5	1
8	Active participation in the new CPMS development, testing and roll-out	83%	100%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	0	908
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	0%	9.6%
16	Mapping of the use of Orphacodes in all clinical units	0,43%	50%
Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	0	1
18	Number of trainees who completed accredited Training Courses	0	48
19	Number of countries of origin of trainees who completed accredited Training Courses	0	19
20	Number of non-accredited training courses developed by the ERN	12	17
21	Number of trainees who completed the non-accredited trainings	545	767

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22	Number of countries of origin of trainees who completed the non-accredited Training Courses	20	20
Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	3	0
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	2	2

Endo-ERN

Endo-ERN works on rare endocrine conditions. It covers Adrenal, Disorders of Calcium & Phosphate Homeostasis, Genetic Disorders of Glucose & Insulin Homeostasis, Genetic Endocrine Tumour Syndromes, Growth & Genetic Obesity Syndromes, Hypothalamic and Pituitary Conditions, Sex Development & Maturation, and Thyroid.

This ERN included 105 healthcare providers located in 27 countries in the EU and Norway, distributed as follows:

- 91 Full Members in 21 Member States
- 11 Associated National Centres in 5 Member States and 2 in Norway
- 1 National Coordination Hub in a Member State

In addition, 20 patient representatives from 10 countries collaborate in the ERN activities. Collaborative agreements are also in place with the 2 main professional scientific societies in the field (European Society of Endocrinology and European Society of Paediatric Endocrinology).

KPI# Endo-ERN Indicators overview

Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	N/A	Yes
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	4991	4375
4	Number of dissemination webinars	16	16
5	Number of webinars attendees	405	393
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	19287	21052
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	161	149
8	Active participation in the new CPMS development, testing and roll-out	100%	92%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	12774	15983
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	66%	76%
16	Mapping of the use of Orphacodes in all clinical units	48%	65%

Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	51	6
18	Number of trainees who completed accredited Training Courses	4765	535
19	Number of countries of origin of trainees who completed accredited Training Courses	40	43
20	Number of non-accredited training courses developed by the ERN	82	25
21	Number of trainees who completed the non-accredited trainings	33127	534
22	Number of countries of origin of trainees who completed the non-accredited Training Courses	40	45

Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	67	2
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	0	5

EpiCARE

ERN EpiCARE works on rare and complex epilepsies. It covers 160 rare forms of epilepsy, mostly of genetic origin, and highly complex cases of focal epilepsies, candidates to a pre-surgical evaluation and epilepsy-surgery.

This ERN included 50 healthcare providers located in 24 countries in the EU and Norway, distributed as follows:

- 38 Full Members in 15 Member States, plus Norway
- 10 Associated National Centres in 6 Member States
- 2 National Coordination Hubs in 2 Member States

In addition, 22 patient representatives (patient associations) collaborate in the ERN activities, and collaborative agreements are in place with the 3 main scientific societies in the field (European section of the International League Against Epilepsy; European Academy of Neurology; European Paediatric Neurology Society).

KPI# EpiCARE Indicators overview

Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	No	Yes
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	1769	1400
4	Number of dissemination webinars	19	13
5	Number of webinars attendees	2437	1210
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	10047	12737
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	131	31
8	Active participation in the new CPMS development, testing and roll-out	83%	75%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	0	6643
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	0%	52%
16	Mapping of the use of Orphacodes in all clinical units	27%	67%
Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	1	1

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18	Number of trainees who completed accredited Training Courses	32	39
19	Number of countries of origin of trainees who completed accredited Training Courses	17	15
20	Number of non-accredited training courses developed by the ERN	389	463
21	Number of trainees who completed the non-accredited trainings	3271	5771
22	Number of countries of origin of trainees who completed the non-accredited Training Courses	0	65

Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	24	24
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	24	1

ERKNet

ERN ERKNet works on rare kidney diseases. It covers Glomerulopathies, Congenital Malformations & Ciliopathies, Tubulopathies, Metabolic & Stone Disorders, Thrombotic Microangiopathies, Paediatric CKD & Dialysis, Paediatric Transplantation, and Rare Causes of Hypertension.

This ERN included 73 healthcare providers located in 24 countries in the EU and Norway, distributed as follows:

- 64 Full Members in 18 Member States
- 7 Associated National Centres in 4 Member States and 1 in Norway
- 2 National Coordination Hubs in 2 Member States

In addition, 29 patients representatives from 23 patient organisations and over 12 countries collaborate in the ERN activities.

KPI# ERKNet Indicators overview

Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	No	Yes
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	8066	6756
4	Number of dissemination webinars	0	3
5	Number of webinars attendees	0	176
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	15530	6883
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	6	7
8	Active participation in the new CPMS development, testing and roll-out	58%	25%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	5608	4982
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	36%	72%
16	Mapping of the use of Orphacodes in all clinical units	51%	96%
Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	0	0

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18	Number of trainees who completed accredited Training Courses	0	0
19	Number of countries of origin of trainees who completed accredited Training Courses	0	0
20	Number of non-accredited training courses developed by the ERN	45	68
21	Number of trainees who completed the non-accredited trainings	910	1611
22	Number of countries of origin of trainees who completed the non-accredited Training Courses	72	24

Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	55	65
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	8	5

ERN-EYE

ERN-EYE works on rare eye diseases. It covers Retinal Diseases, Neuro ophthalmology, Paediatric Rare Eye Diseases, and Anterior Segment.

This ERN included 59 healthcare providers located in 24 EU countries, distributed as follows:

- 51 Full Members in 18 Member States
- 5 Associated National Centres in 3 Member States
- 3 National Coordination Hubs in 3 Member States

In addition, 9 patient representatives collaborate in the ERN activities.

KPI#	ERN-EYE Indicators overview		
	Coordination	2023	2024
1	ERN Member (HCP) Performance Indicator System	No	Yes
	Dissemination	2023	2024
3	Number of downloaded documents from ERN website	N/A	61
4	Number of dissemination webinars	3	3
5	Number of webinars attendees	387	767
	Healthcare and Clinical Patient Management System (CPMS)	2023	2024
6	Number of new patients referred to the HCPs of the ERN within the scope of the ERN	19,074	19,863
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	34	39
8	Active participation in the new CPMS development, testing and roll-out	83%	75%
	Registries: Indicators	2023	2024
10	Number of new patients uploaded to the ERN registry	6	0
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	0%	0%
16	Mapping of the use of Orphacodes in all clinical units	58,18%	62,26%
	Training and Education	2023	2024
17	Number of accredited Training Courses developed by the ERNs	1	2
18	Number of trainees who completed accredited Training Courses	0	10
19	Number of countries of origin of trainees who completed accredited Training Courses	0	6
20	Number of non-accredited training courses developed by the ERN	8	12
21	Number of trainees who completed the non-accredited trainings	1,258	939

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22	Number of countries of origin of trainees who completed non-accredited Training Courses	32	38
Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	0	1
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	7	8

ERN-LUNG

ERN-LUNG works on rare respiratory diseases. It covers Alpha-1 antitrypsin deficiency (AATD), Bronchiectasis (BE), Chronic Lung Allograft Dysfunction (CLAD), Cystic Fibrosis (CF), Interstitial Lung Diseases (ILD), Mesothelioma (MSTO), Other Rare Lung Diseases (ORLD), Primary Ciliary Dyskinesia (PCD), Pulmonary Hypertension (PH), and Sarcoidosis (SARC).

This ERN included 87 healthcare providers located in 25 countries, in the EU and Norway, distributed as follows:

- 78 Full Members in 18 Member States, plus Norway
- 7 Associated National Centres in 4 Member States
- 2 National Coordination Hubs in 2 Member States

KPI#	ERN-LUNG Indicators overview		
	Coordination	2023	2024
1	ERN Member (HCP) Performance Indicator System	No	No
	Dissemination	2023	2024
3	Number of downloaded documents from ERN website	0	0
4	Number of dissemination webinars	12	0
5	Number of webinars attendees	420	0
	Healthcare and Clinical Patient Management System (CPMS)	2023	2024
6	Number of new patients referred to the HCPs of the ERN within the scope of the ERN	14322	16554
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	8	8
8	Active participation in the new CPMS development, testing and roll-out	100%	83%
	Registries: Indicators	2023	2024
10	Number of new patients uploaded to the ERN registry	1843	2091
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	13%	13%
16	Mapping of the use of Orphacodes in all clinical units	1%	64%
	Training and Education	2023	2024
17	Number of accredited Training Courses developed by the ERNs	561	153
18	Number of trainees who completed accredited Training Courses	0	10298
19	Number of countries of origin of trainees who completed accredited Training Courses	0	26
20	Number of non-accredited training courses developed by the ERN	705	116

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21	Number of trainees who completed the non-accredited trainings	31	9885
22	Number of countries of origin of trainees who completed non-accredited Training Courses	15	26

Clinical Practice Guidelines and other Clinical Decision Support Tools

2023

2024

23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	257	43
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	0	0

ERN-RND

ERN-RND works on rare neurological diseases. It covers Ataxia and Hereditary Spastic Paraplegias, Huntington's Disease and Chorea, Dystonia, paroxysmal disorders and Neurodegeneration with Brain Iron Accumulation, Leukoencephalopathies, Atypical parkinsonian syndromes, and Frontotemporal dementia.

This ERN included 67 healthcare providers located in 24 EU countries, distributed as follows:

- 63 Full Members in 20 Member States
- 2 Associated National Centres in 2 Member States
- 2 National Coordination Hubs in 2 Member States

In addition, 9 patient representatives collaborate in the ERN activities.

KPI#	ERN-RND Indicators overview		
	Coordination	2023	2024
1	ERN Member (HCP) Performance Indicator System	No	Yes
	Dissemination	2023	2024
3	Number of downloaded documents from ERN website	612	1032
4	Number of dissemination webinars	0	0
5	Number of webinars attendees	0	0
	Healthcare and Clinical Patient Management System (CPMS)	2023	2024
6	Number of new patients referred to the HCPs of the ERN within the scope of the ERN	9302	7439
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	82	80
8	Active participation in the new CPMS development, testing and roll-out	92%	100%
	Registries: Indicators	2023	2024
10	Number of new patients uploaded to the ERN registry	4960	8116
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	53%	109%
16	Mapping of the use of Orphacodes in all clinical units	53%	68%
	Training and Education	2023	2024
17	Number of accredited Training Courses developed by the ERNs	12	18
18	Number of trainees who completed accredited Training Courses	727	1089
19	Number of countries of origin of trainees who completed accredited Training Courses	41	43
20	Number of non-accredited training courses developed by the ERN	4	4
21	Number of trainees who completed the non-accredited trainings	159	178

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22	Number of countries of origin of trainees who completed non-accredited Training Courses	45	35
Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	3	1
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	5	9

ERN-SKIN

ERN-SKIN works on rare, complex and undiagnosed skin disorders. It covers Inherited epidermolysis bullosa and skin fragility syndromes, Darier, Hailey-Hailey, Ichthyosis and palmoplantar keratoderma, Ectodermal dysplasias including incontinentia pigmenti and p63- associated disorders, Mendelian causes of connective tissue disorders, Cutaneous mosaic disorders - nevi and nevoid skin disorders and complex vascular malformations and vascular tumours, Cutaneous diseases related to DNA repair disorders and photosensitivity, Autoimmune bullous diseases severe cutaneous drug reactions, and Hidradenitis suppurativa - PAPA, PAPASH, PASH, PASS, SAPHO - Behçet, Degos. Most of these diseases are very rare, without cure, and patients require several hours of daily care.

This ERN included 56 healthcare providers located in 20 EU countries, distributed as follows:

- 52 Full Members in 16 Member States
- 2 Associated National Centres in 2 Member States
- 2 National Coordination Hubs in 2 Member States

In addition, 16 patient representatives collaborate in the ERN activities.

KPI#	ERN-SKIN Indicators overview		
	Coordination	2023	2024
1	ERN Member (HCP) Performance Indicator System	N/A	No
	Dissemination	2023	2024
3	Number of downloaded documents from ERN website	N/A	27
4	Number of dissemination webinars	9	9
5	Number of webinars attendees	495	2283
	Healthcare and Clinical Patient Management System (CPMS)	2023	2024
6	Number of new patients referred to the HCPs of the ERN within the scope of the ERN	7080	6780
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	42	35
8	Active participation in the new CPMS development, testing and roll-out	92%	100%
	Registries: Indicators	2023	2024
10	Number of new patients uploaded to the ERN registry	9	11
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	0.1%	0.2%
16	Mapping of the use of Orphacodes in all clinical units	51%	68%
	Training and Education	2023	2024
17	Number of accredited Training Courses developed by the ERNs	165	115

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18	Number of trainees who completed accredited Training Courses	10788	6919
19	Number of countries of origin of trainees who completed accredited Training Courses	45	58
20	Number of non-accredited training courses developed by the ERN	217	259
21	Number of trainees who completed the non-accredited trainings	7605	7204
22	Number of countries of origin of trainees who completed non-accredited Training Courses	21	20

Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	28	30
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	27	33

ERNICA

ERNICA works on rare inherited and congenital (digestive and gastrointestinal) anomalies. It covers Oesophageal diseases, Intestinal diseases, Gastroenterological diseases, Intestinal failure, Abdominal wall defects and Malformations of the diaphragm.

This ERN included 52 healthcare providers located in 21 countries, distributed as follows:

- 39 Full Members in 11 Member States, plus Norway
- 9 Associated National Centres in 5 Member States
- 4 National Coordination Hubs in 4 Member States

In addition, 13 patients' organisations and 4 individual parents of patients collaborate in the ERN activities.

KPI#

ERNICA Indicators overview

Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	No	Yes
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	N/A	N/A
4	Number of dissemination webinars	0	0
5	Number of webinars attendees	0	0
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN within the scope of the ERN	4926	3844
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	7	5
8	Active participation in the new CPMS development, testing and roll-out	92%	100%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	584	643
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	12%	17%
16	Mapping of the use of Orphacodes in all clinical units	43%	58%
Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	0	10
18	Number of trainees who completed accredited Training Courses	0	667
19	Number of countries of origin of trainees who completed accredited Training Courses	0	83
20	Number of non-accredited training courses developed by the ERN	22	7
21	Number of trainees who completed the non-accredited trainings	106	77

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22	Number of countries of origin of trainees who completed non-accredited Training Courses	21	17
Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	0	2
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	1	1

EURACAN

ERN EURACAN works on rare adult solid cancers. It covers Connective tissue (sarcomas), Female genital organs and placenta, Male genital organs and urinary tract, Neuroendocrine system, Digestive tract, Endocrine organs, Head and neck, Thorax, Skin and eye melanoma, and Brain and spinal cord.

This ERN includes 100 healthcare providers located in 26 countries in the EU and Norway, distributed as follows:

- 91 Full Members in 18 Member States, plus Norway
- 7 Associated National Centres in 5 Member States
- 2 Coordination Hubs in 2 Member States

In addition, 14 patients' representatives collaborate in the ERN activities.

KPI# EURACAN Indicators overview

Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	No	No
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	0	0
4	Number of dissemination webinars	0	0
5	Number of webinars attendees	0	0
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	45511	41449
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	76	197
8	Active participation in the new CPMS development, testing and roll-out	58%	100%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	6300	14281
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	14%	35%
16	Mapping of the use of Orphacodes in all clinical units	32%	37%
Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	0	0
18	Number of trainees who completed accredited Training Courses	0	0
19	Number of countries of origin of trainees who completed accredited Training Courses	0	0
20	Number of non-accredited training courses developed by the ERN	4	32
21	Number of trainees who completed the non-accredited trainings	4	19

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22	Number of countries of origin of trainees who completed the non-accredited Training Courses	1	7
Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	1	4
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	0	0

EURO-NMD

ERN EURO-NMD works on rare neuromuscular diseases. It covers Muscle Diseases, Neuromuscular Junction disorders, Motor neuron diseases, Peripheral Nerve disorders, and Mitochondrial diseases.

This ERN included 82 healthcare providers located in 25 countries in the EU and Norway, distributed as follows:

- 74 Full Members in 17 Member States, plus Norway
- 6 Associated National Centres in 5 Member States
- 2 National Coordination Hubs in 2 Member States

In addition, 36 patients 'representatives from 28 patient organisations and over 15 countries collaborate in the ERN activities.

KPI# EURO-NMD Indicators overview

Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	No	No
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	56	119
4	Number of dissemination webinars	15	31
5	Number of webinars attendees	1016	2001
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	39178	37239
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	13	6
8	Active participation in the new CPMS development, testing and roll-out	92%	100%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	0	32
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	0%	0%
16	Mapping of the use of Orphacodes in all clinical units	46%	67%
Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	302	221
18	Number of trainees who completed accredited Training Courses	3399	17393
19	Number of countries of origin of trainees who completed accredited Training Courses	0	0
20	Number of non-accredited training courses developed by the ERN	247	166

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21	Number of trainees who completed the non-accredited trainings	0	7432
22	Number of countries of origin of trainees who completed the non-accredited Training Courses	0	0

Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	2	74
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	2	30

ERN-EuroBloodNet

ERN EuroBloodNet works on rare haematological diseases. It covers 4 non-oncological disease areas (paediatrics and adults): Rare Red blood cell defects, Bone marrow failure and hematopoietic disorders, Rare bleeding-coagulation disorders and related diseases, Hemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis; as well as 2 oncological disease areas (adults): Lymphoid malignancies, and Myeloid malignancies.

This ERN included 97 healthcare providers located in 24 EU countries, distributed as follows:

- 90 Full Members in 18 Member States
- 4 Associated National Centres in 3 Member States
- 3 National Coordination Hubs in 3 Member States

In addition, 11 European Patient Advocacy Groups (ePAGs) and 53 national patient organisations collaborate in the ERN activities.

KPI# EuroBloodNet Indicators overview

Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	No	Yes
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	0	3,081
4	Number of dissemination webinars	0	4
5	Number of webinars attendees	0	146
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	22,605	24,176
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	12	5
8	Active participation in the new CPMS development, testing and roll-out	75%	83%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	0	4,686
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	0%	19%
16	Mapping of the use of Orphacodes in all clinical units	39.24%	43.82%
Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	10	99

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18	Number of Trainees who completed accredited Training Courses	355	2,061
19	Number of countries of origin of trainees who completed accredited Training Courses	56	83
20	Number of non-accredited training courses developed by the ERN	72	68
21	Number of trainees who completed the non-accredited trainings	621	564
22	Number of countries of origin of trainees who completed the non-accredited Training Courses	57	43

Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	69	70
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	2	3

eUROGEN

ERN eUROGEN works on rare uro-recto-genital diseases and complex conditions. It covers three Work Streams (WS): WS 1: rare congenital uro-recto-genital anomalies (paediatrics), WS 2: functional uro-recto-genital conditions requiring highly specialised surgery (adults), and WS 3: rare uro-recto-genital tumours.

This ERN included 56 healthcare providers located in 20 EU countries, distributed as follows:

- 51 Full Members in 15 Member States
- 1 Associated National Centre in 1 Member State
- 4 Coordination Hubs in 4 Member States

In addition, 7 patient representatives collaborate in the ERN activities.

KPI#	eUROGEN Indicators overview		
Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	Yes	Yes
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	729	1010
4	Number of dissemination webinars	1	0
5	Number of webinars attendees	0	0
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	12796	13493
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	20	18
8	Active participation in the new CPMS development, testing and roll-out	100%	100%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	171	163
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	1%	1%
16	Mapping of the use of Orphacodes in all clinical units	44%	50%
Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	12	30
18	Number of trainees who completed accredited Training Courses	726	2335
19	Number of countries of origin of trainees who completed accredited Training Courses	77	105
20	Number of non-accredited training courses developed by the ERN	23	1

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21	Number of trainees who completed the non-accredited trainings	1542	51
22	Number of countries of origin of trainees who completed the non-accredited Training Courses	98	22
Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	2	0
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	0	1

ERN GENTURIS

ERN GENTURIS works on rare genetic tumour risk syndromes. It covers Schwannomatosis & neurofibromatosis, Lynch syndrome and polyposis, Hereditary breast and ovarian cancer syndrome, and Other rare – predominantly malignant genturis.

This ERN included 51 healthcare providers located in 23 countries in the EU and Norway, distributed as follows:

- 44 Full Members in 17 Member States
- 4 Associated National Centres in 3 Member States and 1 in Norway
- 2 National Coordination Hubs in 2 Member States

In addition, 10 patient representatives collaborate in the ERN activities.

KPI# ERN GENTURIS Indicators overview

Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	No	Yes
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	N/A	2,714
4	Number of dissemination webinars	N/A	2
5	Number of webinars attendees	N/A	180
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	16,593	20,213
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	56	69
8	Active participation in the new CPMS development, testing and roll-out	100%	100%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	365	1,247
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	2%	6%
16	Mapping of the use of Orphacodes in all clinical units	.45%	52%
Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	1	1
18	Number of Trainees who completed accredited Training Courses	43	77

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19	Number of countries of origin of trainees who completed accredited Training Courses	21	29
20	Number of non-accredited training courses developed by the ERN	14	12
21	Number of trainees who completed the non-accredited trainings	804	589
22	Number of countries of origin of trainees who completed the non-accredited Training Courses	27	27

Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	1	6
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	8	2

GUARD-HEART

ERN GUARD-HEART works on uncommon and rare diseases of the heart. It covers Familial electrical diseases, Familial cardiomyopathies, Special electrophysiology conditions in children, Congenital heart diseases, and Other rare heart diseases.

This ERN included 53 healthcare providers located in 23 EU countries, distributed as follows:

- 44 Full Members in 16 Member States
- 7 Associated National Centres in 5 Member States
- 2 National Coordination Hubs in 2 Member States

In addition, 23 patient representatives (15 European Patient Advocacy Groups and 8 supporting partners) collaborate in the ERN activities.

KPI# GUARD-HEART Indicators overview

Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	No	Yes
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	0	0
4	Number of dissemination webinars	9	9
5	Number of webinars attendees	451	325
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	24,382	24,547
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	43	24
8	Active participation in the new CPMS development, testing and roll-out	92%	67%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	8,793	245
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	36%	1%
16	Mapping of the use of Orphacodes in all clinical units	.32%	43.18%
Training and Education			
17	Number of accredited Training Courses developed by the ERNs	2	1
18	Number of Trainees who completed accredited Training Courses	250	152
19	Number of countries of origin of trainees who completed accredited Training Courses	37	36
20	Number of non-accredited training courses developed by the ERN	11	25

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21	Number of trainees who completed the non-accredited trainings	205	564
22	Number of countries of origin of trainees who completed the non-accredited Training Courses	20	20
Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	18	20
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	6	2

ITHACA

ERN ITHACA works on rare malformation syndromes, intellectual and other neurodevelopmental disorders. It covers both developmental anomalies (DA) and neurodevelopmental disorders (NDD) of genetic, genomic/chromosomal or environmental origin, and those resulting from teratogen exposure. Disorders of human development covers: Congenital malformations (single/multiple) and dysmorphisms, Spina bifida and related dysraphisms (shared area with ERN eUROGEN), Foetal medicine (Prenatal diagnosis of foetal anomalies, Foetal surgery for spinal bifida, Foetal pathology, and Disorders of monozygotic twinning). Disorders of human neurodevelopment covers: Intellectual disability, Autism spectrum disorder, and Psychiatric manifestations of developmental disorders.

This ERN included 71 healthcare providers located in 26 countries in the EU and Norway, distributed as follows:

- 66 Full Members in 21 Member States
- 1 Associated National Centre in 1 Member State and 1 in Norway
- 3 National Coordination Hubs in 3 Member States

In addition, over 60 national or European Patient Advocacy Groups collaborate in the ERN activities.

KPI# ITHACA Indicators overview

Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	No	Yes
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	2176	3109
4	Number of dissemination webinars	7	8
5	Number of webinars attendees	591	553
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN within the scope of the ERN	54765	75197
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	3	3
8	Active participation in the new CPMS development, testing and roll-out	83%	75%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	0	0
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	0%	0%
16	Mapping of the use of Orphacodes in all clinical units	1%	79%

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Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	8	8
18	Number of trainees who completed accredited Training Courses	160	160
19	Number of countries of origin of trainees who completed accredited Training Courses	1	1
20	Number of non-accredited training courses developed by the ERN	220	404
21	Number of trainees who completed the non-accredited trainings	410	172
22	Number of countries of origin of trainees who completed non-accredited Training Courses	20	20
Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	1	1
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	13	2

MetabERN

ERN MetabERN works on hereditary metabolic disorders. It covers AOA - Amino and Organic acids-related disorders, C-FAO - Carbohydrate, fatty acid oxidation and ketone bodies disorders, CDG - Congenital Disorders of Glycosylation and disorders of intracellular trafficking, LSD - Lysosomal Storage disorders, NOMS - Disorders of neuromodulators and other small molecule, PD - Peroxisomal disorders, and PM-MD -Pyruvate metabolism mitochondrial oxidative phosphorylation disorders, Krebs cycle defects, disorders of thiamine transport & metabolism.

This ERN included 91 healthcare providers located in 27 countries in the EU and Norway, distributed as follows:

- 85 Full Members in 23 Member States, plus Norway
- 4 Associated National Centres in 1 Member State
- 2 National Coordination Hubs in 2 Member States

KPI#	MetabERN Indicators overview		
	Coordination	2023	2024
1	ERN Member (HCP) Performance Indicator System	No	No
	Dissemination	2023	2024
3	Number of downloaded documents from ERN website	1101	1521
4	Number of dissemination webinars	73	55
5	Number of webinars attendees	3934	2137
	Healthcare and Clinical Patient Management System (CPMS)	2023	2024
6	Number of new patients referred to the HCPs of the ERN within the scope of the ERN	4322	5770
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	15	17
8	Active participation in the new CPMS development, testing and roll-out	42%	8%
	Registries: Indicators	2023	2024
10	Number of new patients uploaded to the ERN registry	776	319
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	18%	6%
16	Mapping of the use of Orphacodes in all clinical units	1%	64%
	Training and Education	2023	2024
17	Number of accredited Training Courses developed by the ERNs	333	262
18	Number of trainees who completed accredited Training Courses	22800	22204

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19	Number of countries of origin of trainees who completed accredited Training Courses	30	54
20	Number of non-accredited training courses developed by the ERN	440	383
21	Number of trainees who completed the non-accredited trainings	21527	12854
22	Number of countries of origin of trainees who completed non-accredited Training Courses	30	38

Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	107	114
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	36	40

PaedCan

ERN PaedCan works on paediatric cancers. It covers Leukaemia, Brain Tumours, Lymphomas, Neuroblastoma, Renal Tumours, Soft Tissue Sarcomas, Bone Sarcomas, Liver Tumours, Germ Cell Tumours, Retinoblastoma, and Very Rare Tumours (paediatric and adolescent and young adult population).

This ERN included 90 healthcare providers located in 27 countries in the EU and Norway, distributed as follows:

- 79 Full Members in 20 Member States, plus Norway
- 9 Associated National Centres in 5 Member States
- 2 National Coordination Hubs in 2 Member States

In addition, ERN PaedCan closely collaborates with Childhood Cancer International Europe, the largest pan-European childhood cancer parents' and survivors' organisation, representing 64 national organisations in 35 countries. It is involved in the governance of the network, with representation in the Oversight Committee.

KPI# PaedCan Indicators overview

Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	Yes	Yes
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	25	325
4	Number of dissemination webinars	6	3
5	Number of webinars attendees	219	201
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	10,755	9,879
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	145	94
8	Active participation in the new CPMS development, testing and roll-out	92%	92%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	21	55
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	0%	1%
16	Mapping of the use of Orphacodes in all clinical units	25%	34.57%
Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	401	323

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18	Number of Trainees who completed accredited Training Courses	3,475	2,872
19	Number of countries of origin of trainees who completed accredited Training Courses	36	19
20	Number of non-accredited training courses developed by the ERN	226	432
21	Number of trainees who completed the non-accredited trainings	1,966	1,983
22	Number of countries of origin of trainees who completed the non-accredited Training Courses	42	24

Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	24	26
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	27	28

RARE-LIVER

ERN RARE-LIVER works on rare hepatological diseases. It covers Autoimmune liver diseases, Metabolic, biliary atresia and related disease, and Structural liver disease.

This ERN included 62 healthcare providers located in 23 countries in the EU and Norway, distributed as follows:

- 52 Full Members in 15 Member States
- 7 Associated National Centres in 4 Member States and 1 in Norway
- 3 National Coordination Hubs in 3 Member States

In addition, 15 patient representatives collaborate in the ERN activities.

KPI# RARE-LIVER Indicators overview

Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	No	No
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	2,321	1,624
4	Number of dissemination webinars	4	6
5	Number of webinars attendees	719	969
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	8,654	8,560
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	45	65
8	Active participation in the new CPMS development, testing and roll-out	100%	100%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	874	514
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	10%	6%
16	Mapping of the use of Orphacodes in all clinical units	.41%	48.33%
Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	88	103
18	Number of Trainees who completed accredited Training Courses	11,667	9,797
19	Number of countries of origin of trainees who completed accredited Training Courses	28	30
20	Number of non-accredited training courses developed by the ERN	106	115
21	Number of trainees who completed the non-accredited trainings	5,656	5,919

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22	Number of countries of origin of trainees who completed the non-accredited Training Courses	30	30
Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	6	2
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	11	13

ReCONNET

ERN ReCONNET works on rare connective tissue and musculoskeletal diseases. It covers Antiphospholipid Syndrome, Ehlers-Danlos Syndromes, Idiopathic Inflammatory Myopathies, IgG4-Related Diseases, Mixed Connective Tissue Diseases, Relapsing Polychondritis, Sjögren' Syndrome, Systemic Lupus Erythematosus, Systemic Sclerosis, and Undifferentiated Connective Tissue Diseases.

This ERN included 63 healthcare providers located in 23 EU countries, distributed as follows:

- 54 Full Members in 15 Member States
- 6 Associated National Centres in 5 Member States
- 3 National Coordination Hubs in 3 Member States

In addition, 19 patient representatives collaborate in the ERN activities.

KPI# ReCONNET Indicators overview

Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	Yes	Yes
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	612	1,961
4	Number of dissemination webinars	11	33
5	Number of webinars attendees	758	6,518
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	14,691	12,986
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	9	7
8	Active participation in the new CPMS development, testing and roll-out	100%	100%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	0	0
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	0%	0%
16	Mapping of the use of Orphacodes in all clinical units	43%	46%
Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	61	73
18	Number of Trainees who completed accredited Training Courses	3,675	4,432

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19	Number of countries of origin of trainees who completed accredited Training Courses	58	51
20	Number of non-accredited training courses developed by the ERN	259	195
21	Number of trainees who completed the non-accredited trainings	3,323	4,161
22	Number of countries of origin of trainees who completed the non-accredited Training Courses	65	65

Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	214	214
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	14	14

RITA

ERN RITA works on rare immunodeficiency, autoinflammatory, autoimmune, and paediatric rheumatic diseases. It covers Primary immunodeficiencies, Autoinflammatory disorders, Autoimmune diseases, and Paediatric rheumatic diseases.

This ERN included 70 healthcare providers located in 25 countries in the EU and Norway, distributed as follows:

- 61 Full Members in 18 Member States, plus Norway
- 7 Associated National Centres in 4 Member States
- 2 National Coordination Hubs in 2 Member States

In addition, 12 patient representatives collaborate in the ERN activities.

KPI#

RITA Indicators overview

Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	No	Yes
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	670	855
4	Number of dissemination webinars	12	1
5	Number of webinars attendees	994	117
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	19,395	20,887
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	51	28
8	Active participation in the new CPMS development, testing and roll-out	92%	92%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	0	0
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	0%	0%
16	Mapping of the use of Orphacodes in all clinical units	.45%	53.19 %
Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	392	294

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18	Number of Trainees who completed accredited Training Courses	7,384	4,751
19	Number of countries of origin of trainees who completed accredited Training Courses	79	75
20	Number of non-accredited training courses developed by the ERN	1,079	1,121
21	Number of trainees who completed the non-accredited trainings	14,070	16,980
22	Number of countries of origin of trainees who completed the non-accredited Training Courses	50	82

Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	149	67
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	118	156

TRANSPLANT-CHILD

ERN TRANSPLANT-CHILD works on transplantation in children. It covers Solid organ transplantation (heart, lung, kidney, liver and intestinal), and Haematopoietic stem cell transplantation.

This ERN included 40 healthcare providers located in 21 countries in the EU and Norway, distributed as follows:

- 33 Full Members in 13 Member States, plus Norway
- 4 Associated National Centres in 4 Member States
- 3 National Coordination Hubs in 3 Member States

In addition, 13 patient representatives collaborate in the ERN activities.

KPI# TRANSPLANT-CHILD Indicators overview

Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	No	Yes
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	185	648
4	Number of dissemination webinars	3	4
5	Number of webinars attendees	76	100
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	2,067	1,987
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	99	23
8	Active participation in the new CPMS development, testing and roll-out	92%	100%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	151	206
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	7%	10%
16	Mapping of the use of Orphacodes in all clinical units	.53%	50%
Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	74	39
18	Number of Trainees who completed accredited Training Courses	292	596
19	Number of countries of origin of trainees who completed accredited Training Courses	25	20
20	Number of non-accredited training courses developed by the ERN	64	67

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21	Number of trainees who completed the non-accredited trainings	179	711
22	Number of countries of origin of trainees who completed the non-accredited Training Courses	35	25
Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	2	0
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	2	2

VASCERN

ERN VASCERN works in rare multisystemic vascular diseases. It covers Hereditary haemorrhagic telangiectasia, Heritable thoracic aortic diseases, Medium sized arteries (vascular Ehlers Danlos Syndrome ...), Neurovascular diseases (e.g. Moyamoya disease, CADASIL), Paediatric and primary lymphoedema, and Vascular anomalies (malformations, fistulas).

This ERN included 46 healthcare providers located in 19 countries in the EU and Norway, distributed as follows:

- 40 Full Members in 13 Member States, plus Norway
- 4 Associated National Centres in 3 Member States
- 2 National Coordination Hubs in 2 Member States

In addition, 37 patient representatives and 75 patient organisations collaborate in the ERN activities.

KPI# VASCERN Indicators overview

Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	No	No
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	0	4880
4	Number of dissemination webinars	0	7
5	Number of webinars attendees	0	619
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN within the scope of the ERN	6852	6587
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	60	54
8	Active participation in the new CPMS development, testing and roll-out	92%	75%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	1162	435
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	17%	7%
16	Mapping of the use of Orphacodes in all clinical units	53%	60%
Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	14	88
18	Number of trainees who completed accredited Training Courses	120	5646
19	Number of countries of origin of trainees who completed accredited Training Courses	19	32
20	Number of non-accredited training courses developed by the ERN	154	142
21	Number of trainees who completed the non-accredited trainings	518	3403

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22	Number of countries of origin of trainees who completed non-accredited Training Courses	24	35
Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	1	1
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	38	30



Chapter 2

Country Profiles



European
Reference
Networks

The ERNs are networks of healthcare providers located in all 27 EU Member States and Norway. The table below provides an overview of the current level of Member States and Norway's participation across the Networks.

ERN Centres	AT	BE	BG	CY	CZ	DE	DK	EE	ES	FI	FR	GR	HR	HU	IE	IT	LT	LU	LV	MT	NL	NO	PL	PT	RO	SE	SI	SK	MS not covered
BOND	1	2			1	7	3		4	1	5			1	1	11	2	1		1	4	1		2		1	1		9
CRANIO	1	3			1	2	2		3	1	3			2	1	7	1	1	1	1	4	2	1	1		3	1		7
Endo-ERN	2	7	2	1	2	13	3	1	5	1	9	3	2	1	1	20	1	1	2	1	9	2	4	3	4	2	1	2	0
EpiCARE	2	2		1	2	4	2	2	3	2	6		2	1		7	2	1	1	1	1	1	3	1	1	1	1		4
ERKNet	2	3			2	11	3	2	5	1	7	1		1	1	15	1	1	2	1	6	1	3	1	1	1	2		4
ERN-EYE	3	3			1	8	2	2	7	1	6		1	1	1	9	1	1	1	1	4		1	1	1	1	1	1	4
ERNICA	4	3			1	6	2	1	3	1	6		1	1		6	2	1	1	1	5	1	2			3	1		7
ERN-LUNG	3	6		1	4	11	2	1	4	1	5		1	2	1	23	2	1	1	1	7	1	2	3		2	1	1	3
ERN-RND	1	4	1	1	4	9	2	1	8	1	5	1	1	3	1	9	1	1	1	1	6		2			2	1		4
ERN-SKIN	2	3			4	8	2		1	1	6		1	3	1	12	1	1	1	1	5				1	1	1		8
EURACAN	1	6		1	4	8	1	2	6	2	13	1	2	1	1	26	2	1	1	1	9	1	3	3	1	3	1		2
EuroBloodNet	2	6	2	1	3	10	2	1	4	1	11	4		1	1	33	1	1		1	5		2	2		1	1	1	4
eUROGEN	1	3			2	11	2		7	1	2		1	1		7	1	1	1	1	6		2	1		4	1		8
EURO-NMD	2	5	1	1	2	10	2	1	7	2	9	1		2	1	20	1	1	1	1	6	1	1	1		2	1		3
GENTURIS	2	4		1	2	6	2	1	2	2	2	1		1		9	1	1	1	1	5	1	1	3		1	1		5
GUARD-HEART	2	3			2	2	2	1	7	1	5		1	1	1	10	2	1		1	4		1	3	1	1	1	1	5
ITHACA	1	5		1	1	9	3	1	3	2	8		1	2	1	13	1	1	1	1	6	1	3	2	1	1	1	1	2
MetabERN	4	6	1		1	11	1	1	7	1	10	1	1	1	1	18	1	1	1	1	6	2	3	6	1	2	1	1	1
PaedCAN	1	4	1	1	2	19	2	2	6	4	7	1	3	2	1	12	1	1	1	1	2	1	6	2	2	3	1	1	0
RARE-LIVER	1	4			1	10	2	1	3	1	5	1	2	2		13	1	1	2	1	3	1	2	2		2	1		5
ReCONNET	1	3			1	4	1	1	3	1	7	1	1	1		20	1	1	2	1	6		1	3	1	1	1		5
RITA	3	2			2	11	2	1	4	1	5	2	1	1	1	14	2	1	1	1	5	1	3	2		2	1	1	3
TRANSPLANTCHILD	1	2			2	2	1	6	1	2		1	1	1	5	1	1	1	1	1	3	1	1	3		3			7
VASCERN	2	5		1		5	3		2	1	4			1	1	7	1	1		1	6	1		1		2	1		9

ERNs not covered 0 0 18 13 2 0 0 5 0 0 0 12 7 0 6 0 0 0 4 0 0 7 3 3 13 0 1 15

Figure 2. Overview of Member State Participation across all 24 ERNs.

The purpose of this chapter is to provide a country profile of each Member State and Norway, illustrating the participation of Coordinators, Members and Affiliated Partners across the ERNs, the use of Orphacode and new patients referred to the ERNs centres. Data which was submitted outside of the data collection monitoring platform will not be reflected in below.

The figures below refer to the situation on 31/12/2024.

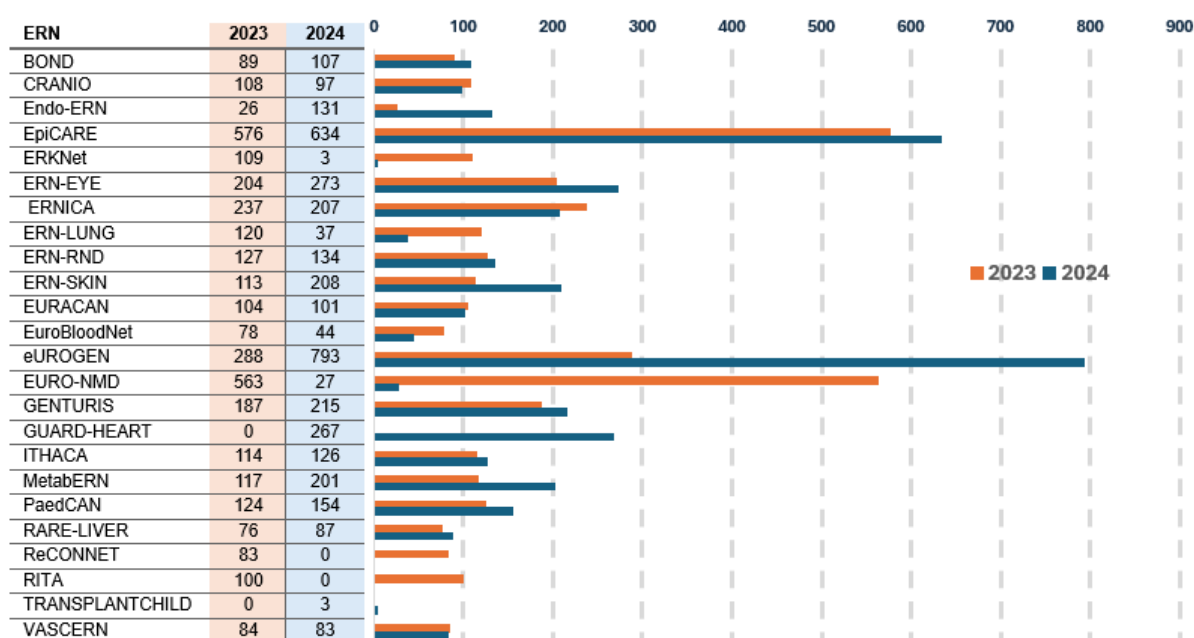
'N/A' signifies no participation in the ERN. '0' signifies participation in the ERN but the reported number was 0.

In the table on mapping the use of Orphacodes, 'N/A' reflects a specific situation of the clinical centre whereby implementation is not in place due to specific reasons – or because the disease lacks a specific orphacode or because the use of different classification codes.

Austria

ERN Coordination Role	1 (PAEDCAN)		
ERN Membership	24/24		
Number of Hospitals	15		
Number of Clinical Centres	44	MEMBERS 9 (20%)	AFFILIATED PARTNERS 35 (80%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



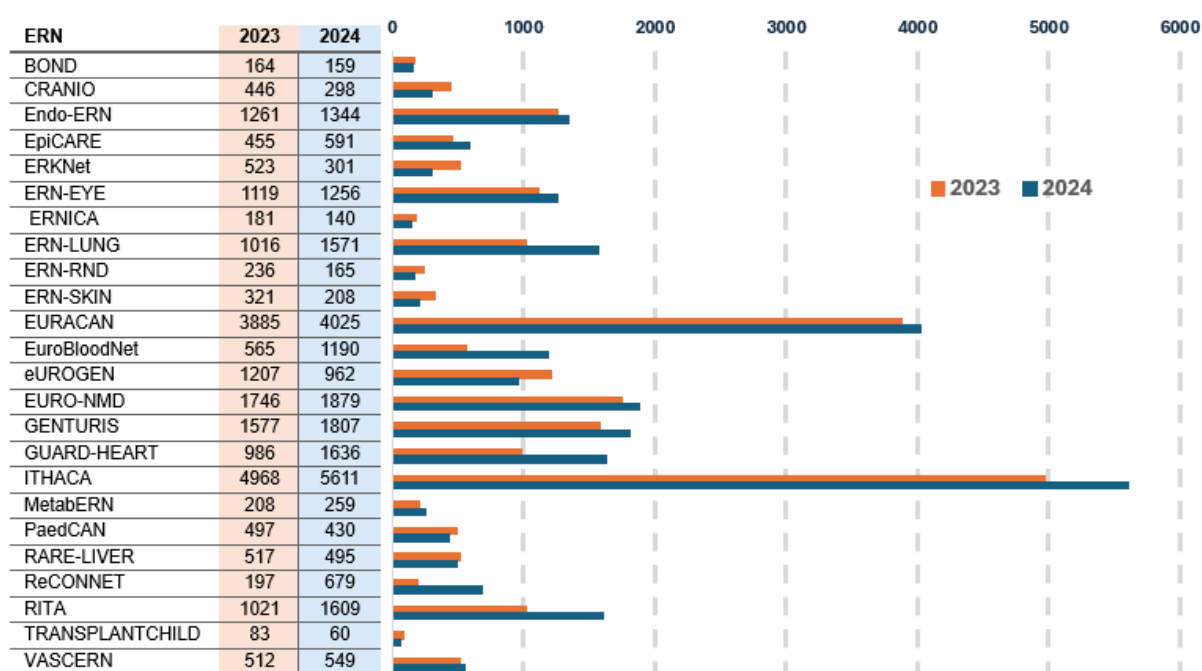
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partner	8	12	16	36
Member	5	4	0	9
Total	13	16	16	45
Percentage	28,8%	35,6%	35,6%	

Belgium

ERN Coordination Role	0		
ERN Membership	24/24		
Number of Hospitals	10		
Number of Clinical Centres	94	MEMBERS 94 (100%)	AFFILIATED PARTNERS 0 (0%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



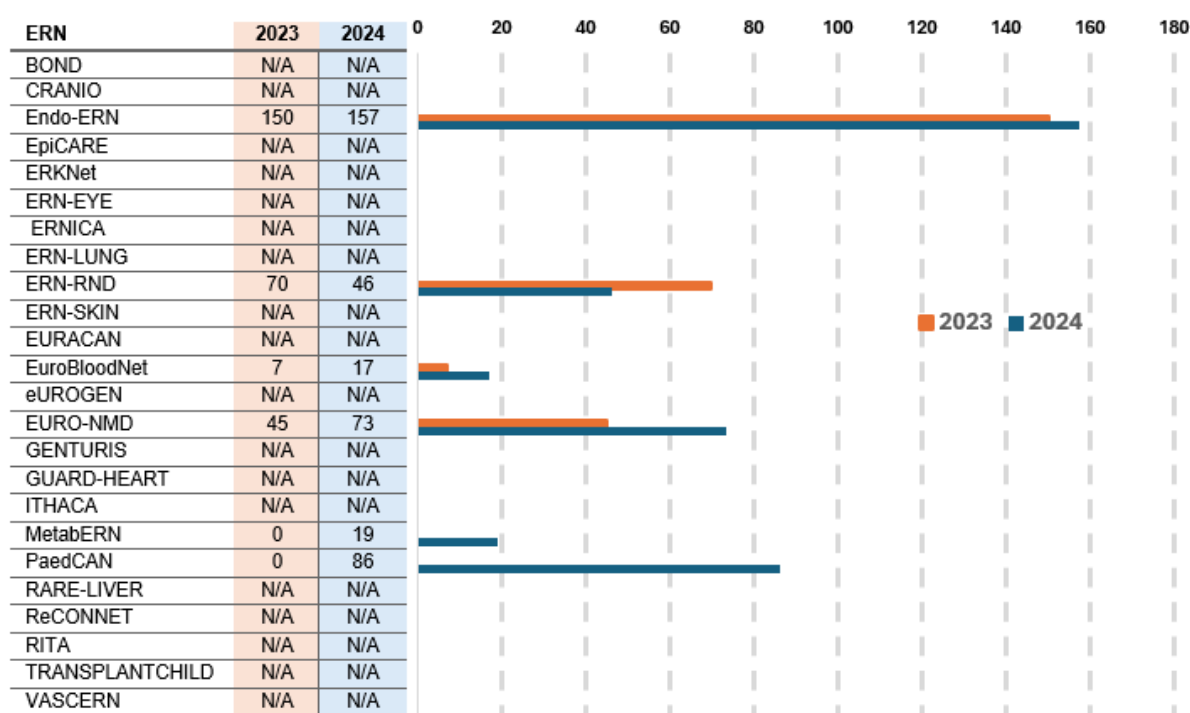
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	-	-	-
Members	67	24	4	95
Total	67	24	4	95
Percentage	70,5%	25,3%	4,2%	

Bulgaria

ERN Coordination Role	0		
ERN Membership	6/24		
Number of Hospitals	8		
Number of Clinical Centres	8	MEMBERS: 7 (88%)	AFFILIATED PARTNERS: 1 (12%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



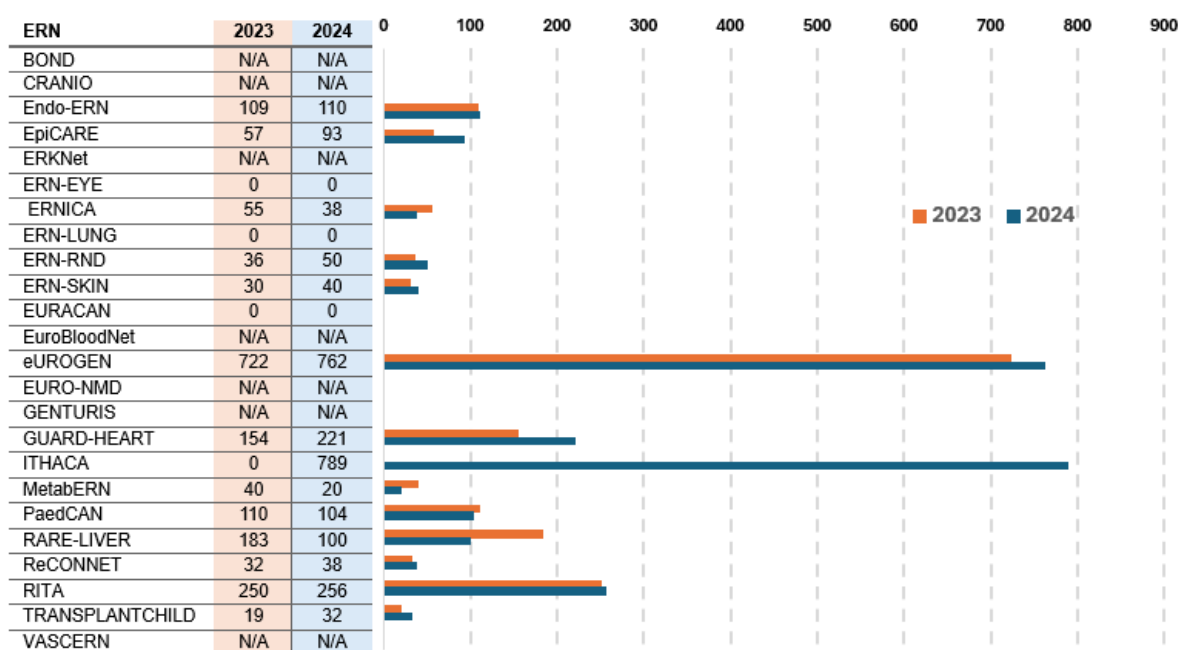
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	1	-	1
Members	1	5	1	7
Total	1	6	1	8
Percentage	12,5%	75%	12,5%	

Croatia

ERN Coordination Role	0		
ERN Membership	17/24		
Number of Hospitals	7		
Number of Clinical Centres	23	MEMBERS 7 (30%)	AFFILIATED PARTNERS 16 (70%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



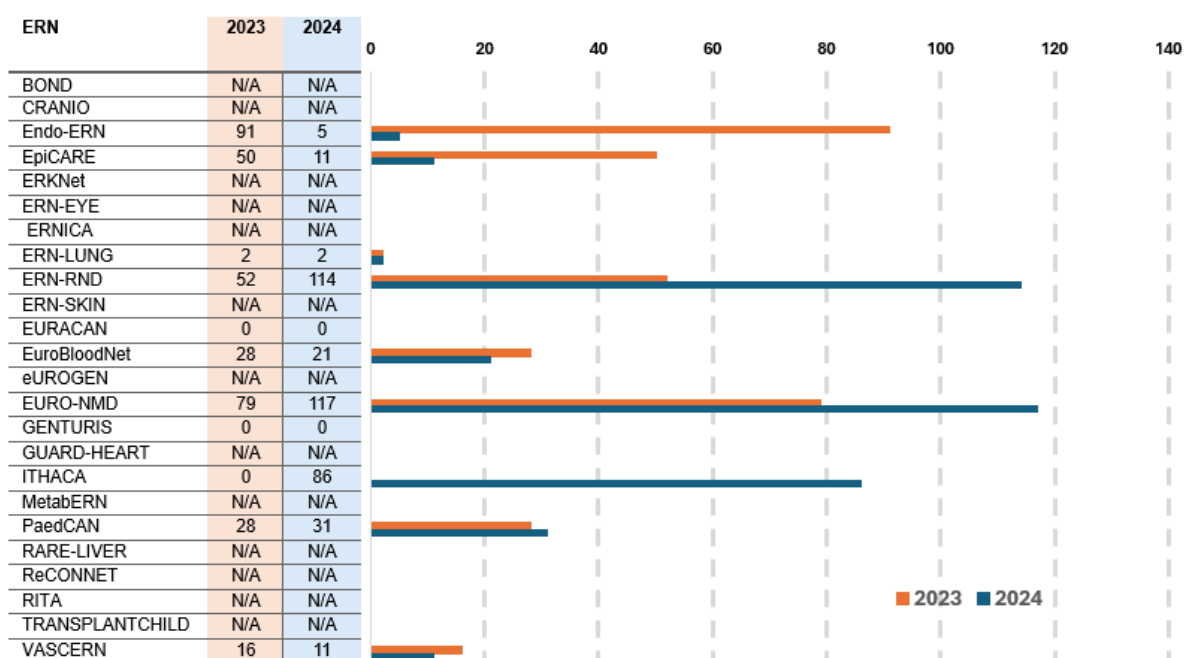
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	9	7	16
Members	2	4	1	7
Total	2	13	8	23
Percentage	8,7%	56,5%	34,8%	

Cyprus

ERN Coordination Role	0		
ERN Membership	11/24		
Number of Hospitals	3		
Number of Clinical Centres	11	MEMBERS 4 (36%)	AFFILIATED PARTNERS 7 (64%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



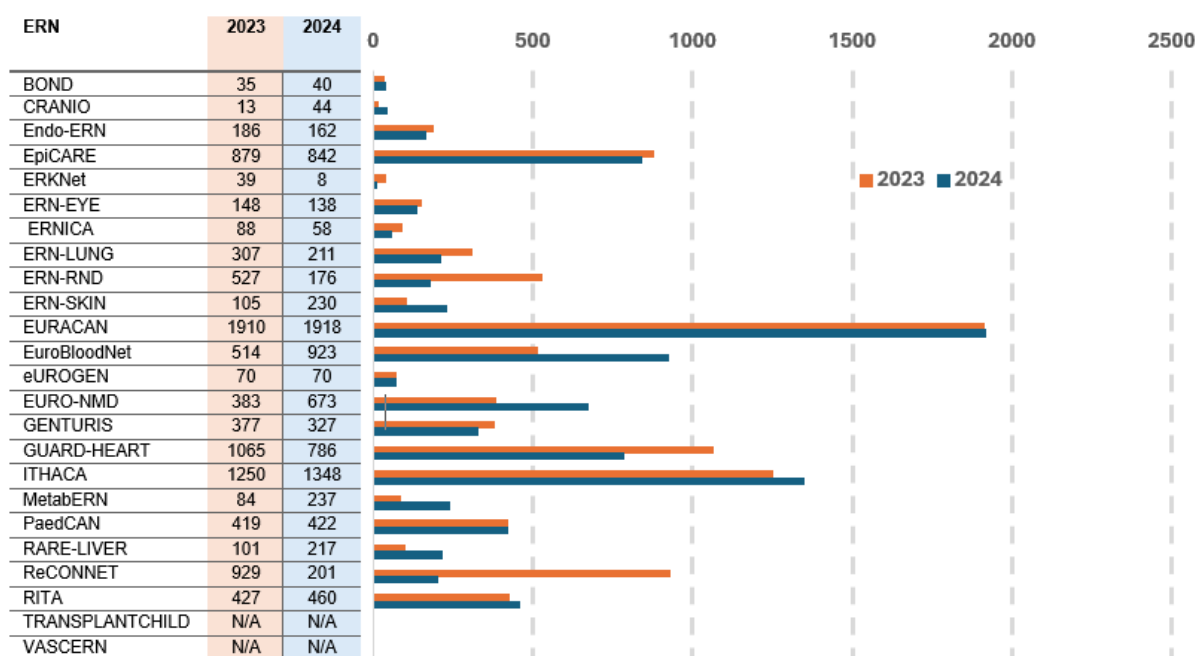
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	4	1	2	7
Members	2	2	-	4
Total	6	3	2	11
Percentage	54,5%	27,3%	18,2%	

Czech Republic

ERN Coordination Role	0		
ERN Membership	22/24		
Number of Hospitals	13		
Number of Clinical Centres	45	MEMBERS 45 (100%)	AFFILIATED PARTNERS 0 (0%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



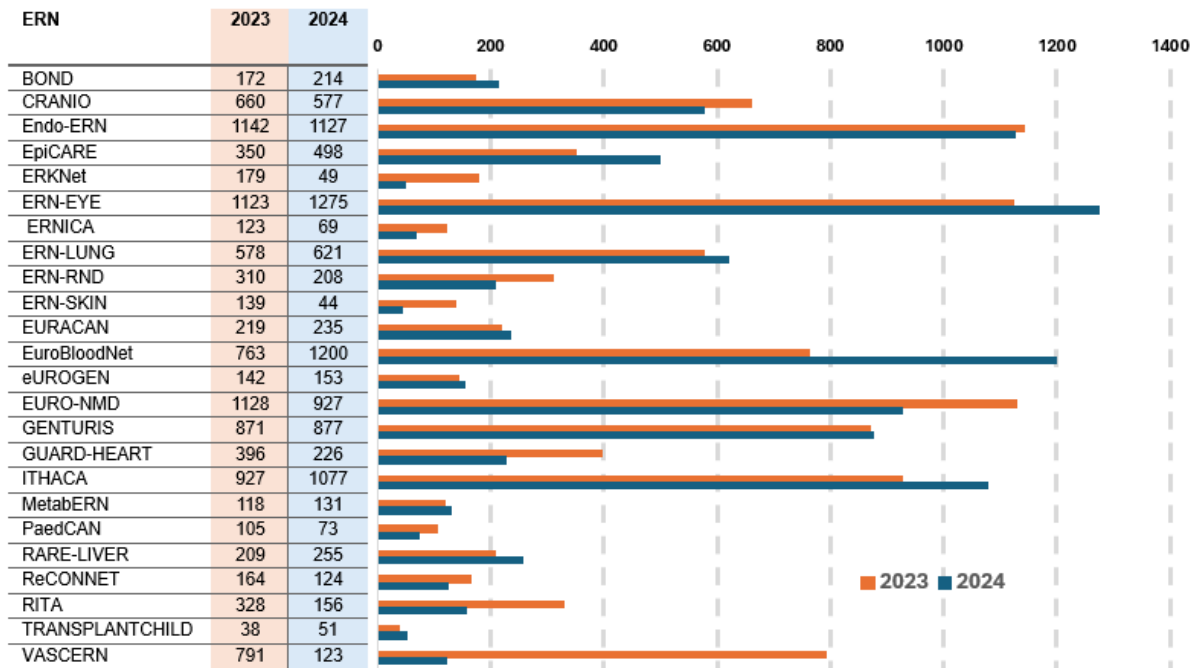
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	-	-	-
Members	37	-	8	45
Total	37	-	8	45
Percentage	82,2%	-	17,8%	

Denmark

ERN Coordination Role	0		
ERN Membership	24/24		
Number of Hospitals	4		
Number of Clinical Centres	50	MEMBERS: 46 (92%)	AFFILIATED PARTNERS: 4 (8%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



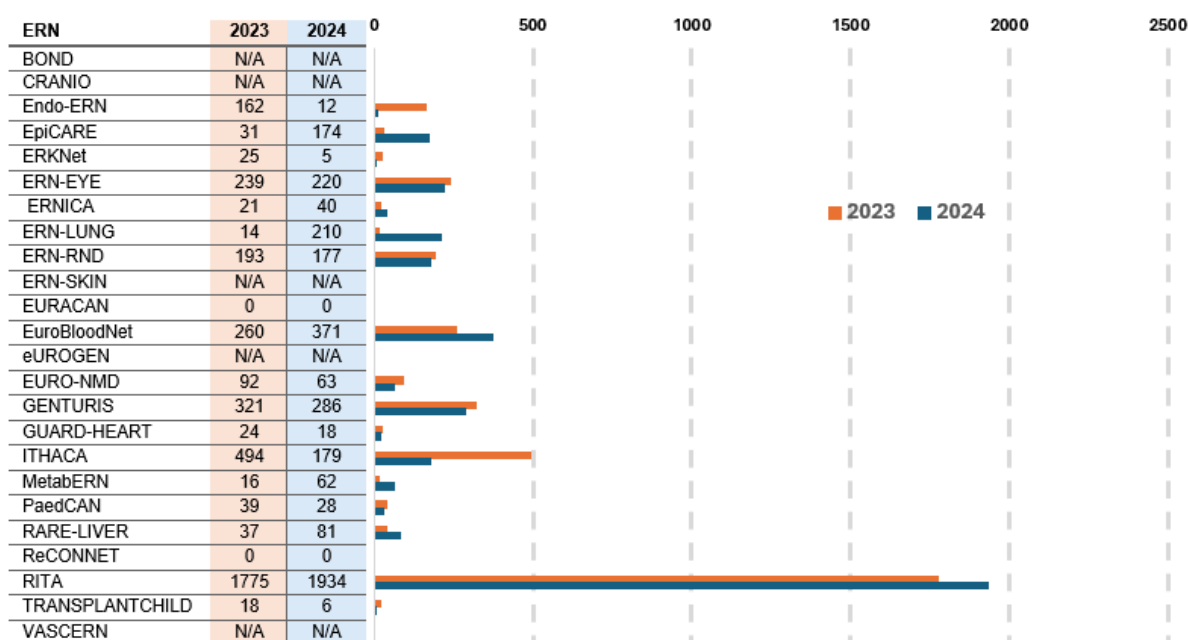
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	1	3	-	4
Members	12	25	9	46
Total	13	28	9	50
Percentage	26%	56%	18%	

Estonia

ERN Coordination Role	0		
ERN Membership	19/24		
Number of Hospitals	4		
Number of Clinical Centres	24	MEMBERS 5 (21%)	AFFILIATED PARTNERS 19 (79%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



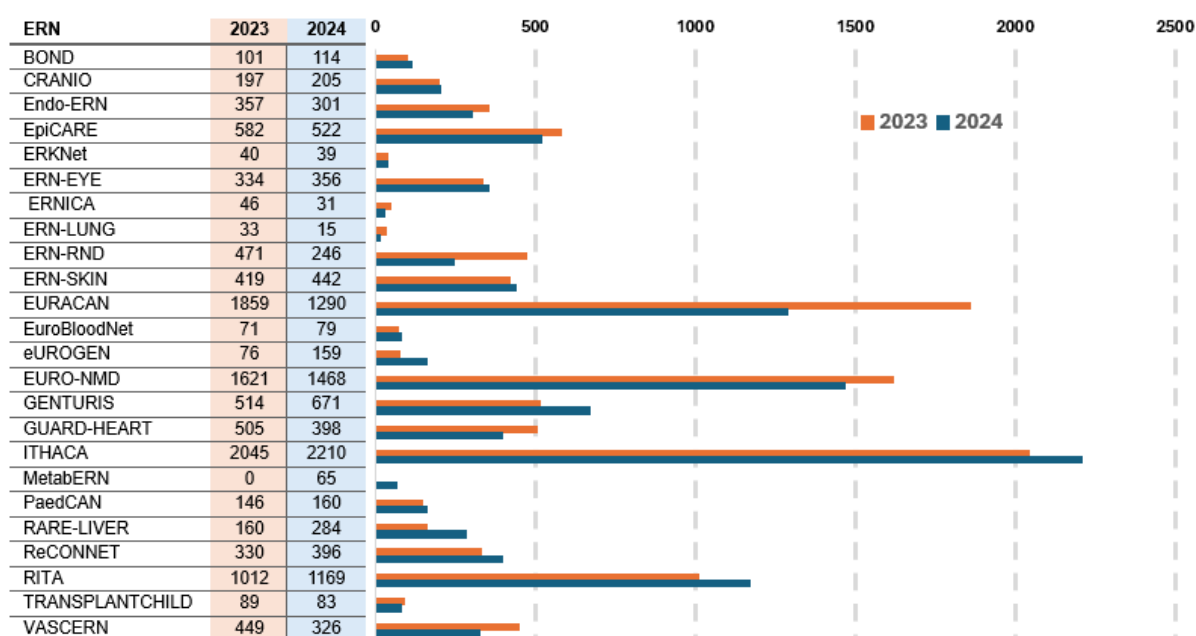
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	4	10	5	19
Members	4	1	-	5
Total	8	11	5	24
Percentage	33%	46%	21%	

Finland

ERN Coordination Role	0		
ERN Membership	24/24		
Number of Hospitals	7		
Number of Clinical Centres	32	MEMBERS 32 (100%)	AFFILIATED PARTNERS 0 (0%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



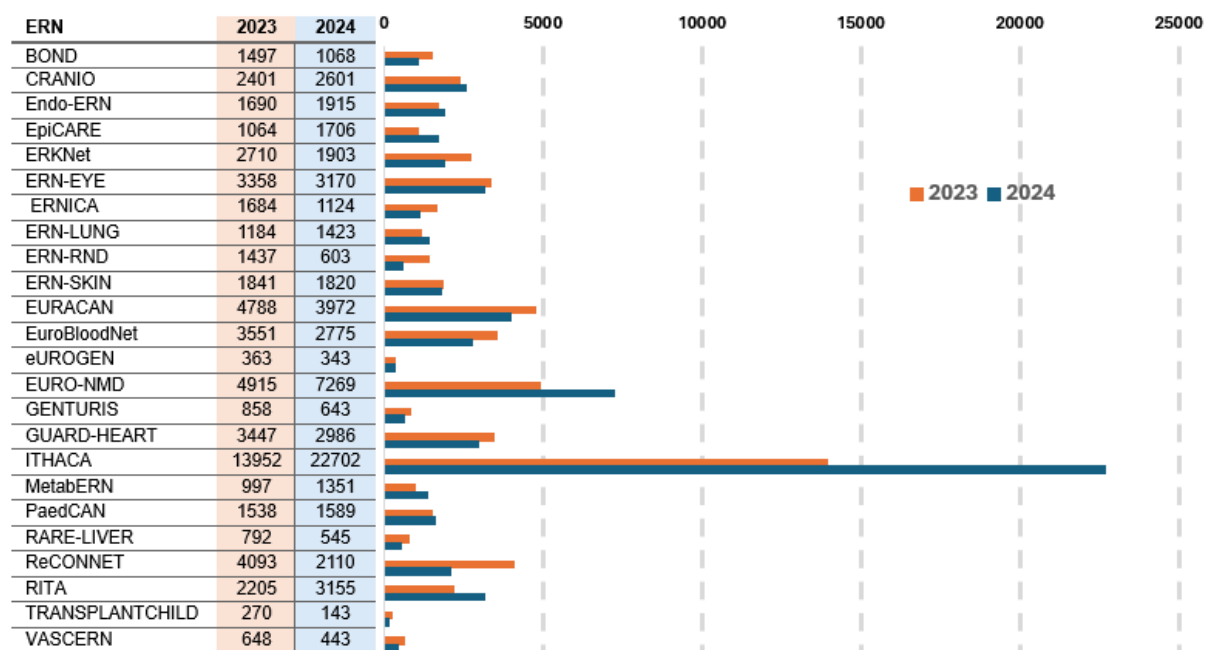
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	-	-	-
Members	26	3	3	32
Total	26	3	3	32
Percentage	81,2%	9,4%	9,4%	

France

ERN Coordination Role	7 (SKIN; EURACAN; EUROBLOODNET; EURO-NMD; EYE; ITHACA; VASCERN)		
ERN Membership	24/24		
Number of Hospitals	44		
Number of Clinical Centres	148	MEMBERS 148 (100%)	AFFILIATED PARTNERS 0 (0%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



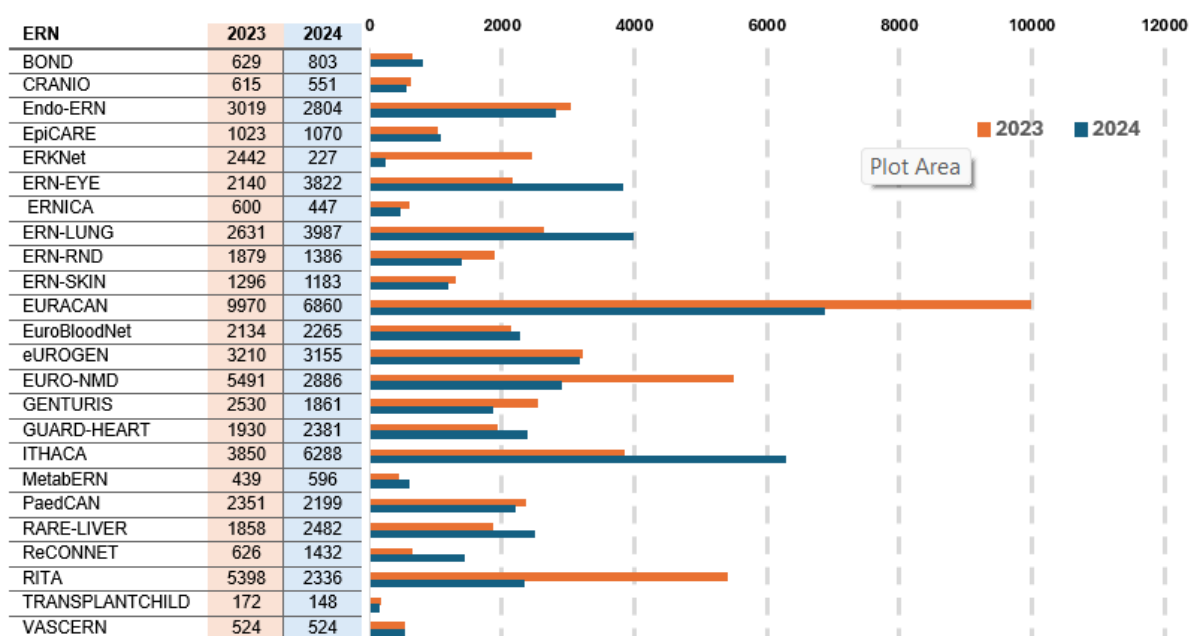
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	-	-	-
Members	105	17	26	148
Total	105	17	26	148
Percentage	70,9%	11,5%	17,6%	

Germany

ERN Coordination Role	4 (ERKNET; RND; LUNG; RARE-LIVER)		
ERN Membership	24/24		
Number of Hospitals	55		
Number of Clinical Centres	197	MEMBERS 197 (100%)	AFFILIATED PARTNERS 0 (0%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



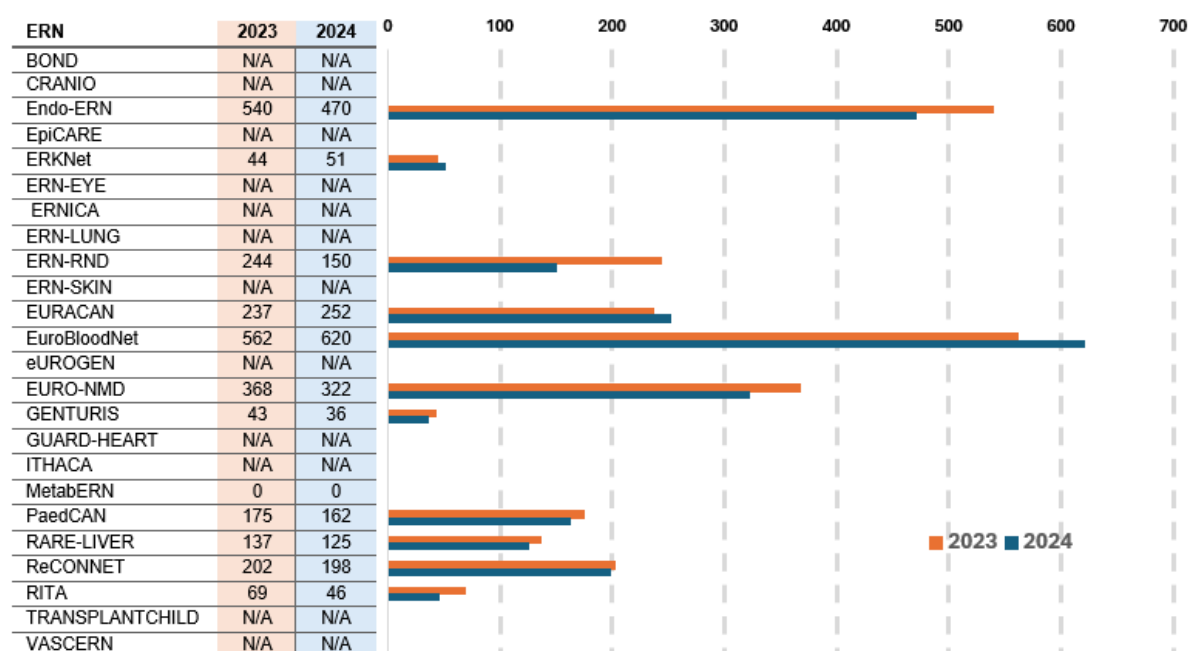
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	-	-	-
Members	125	46	26	197
Total	125	46	26	197
Percentage	63,4%	23,4%	13,2%	

Greece

ERN Coordination Role	0		
ERN Membership	12/24		
Number of Hospitals	7		
Number of Clinical Centres	18	MEMBERS 18 (100%)	AFFILIATED PARTNERS 0 (0%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



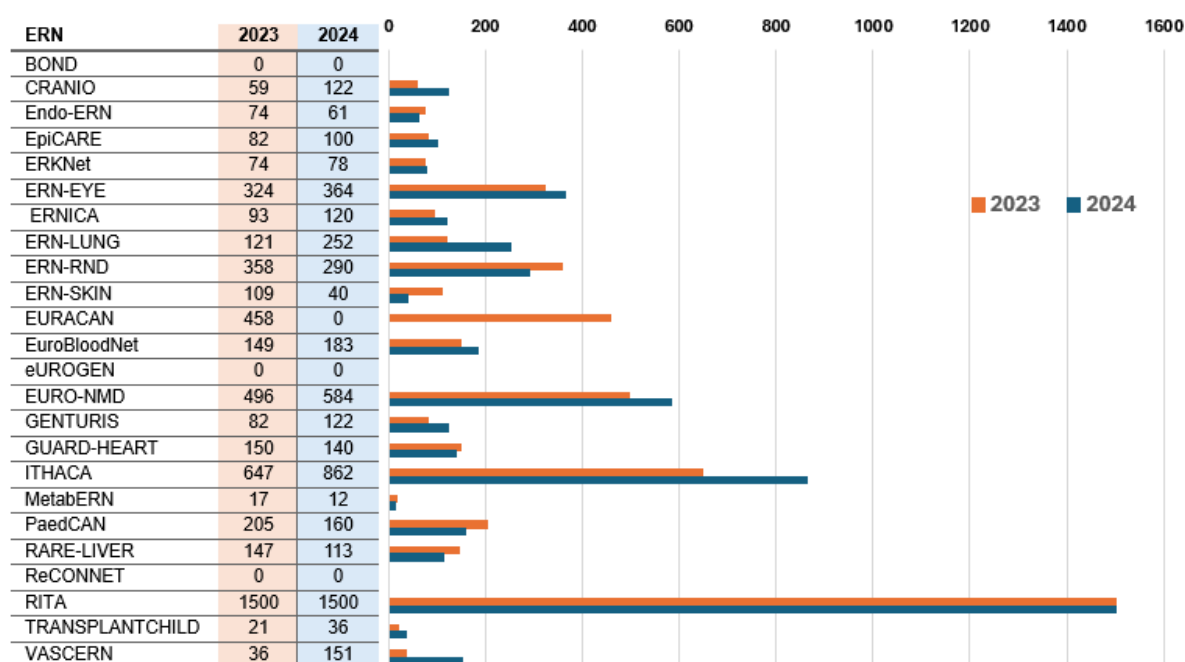
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	-	-	-
Members	10	6	2	18
Total	10	6	2	18
Percentage	55,6	33,3%	11,1%	

Hungary

ERN Coordination Role	0		
ERN Membership	24/24		
Number of Hospitals	8		
Number of Clinical Centres	34	MEMBERS 28 (82%)	AFFILIATED PARTNERS 6 (18%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



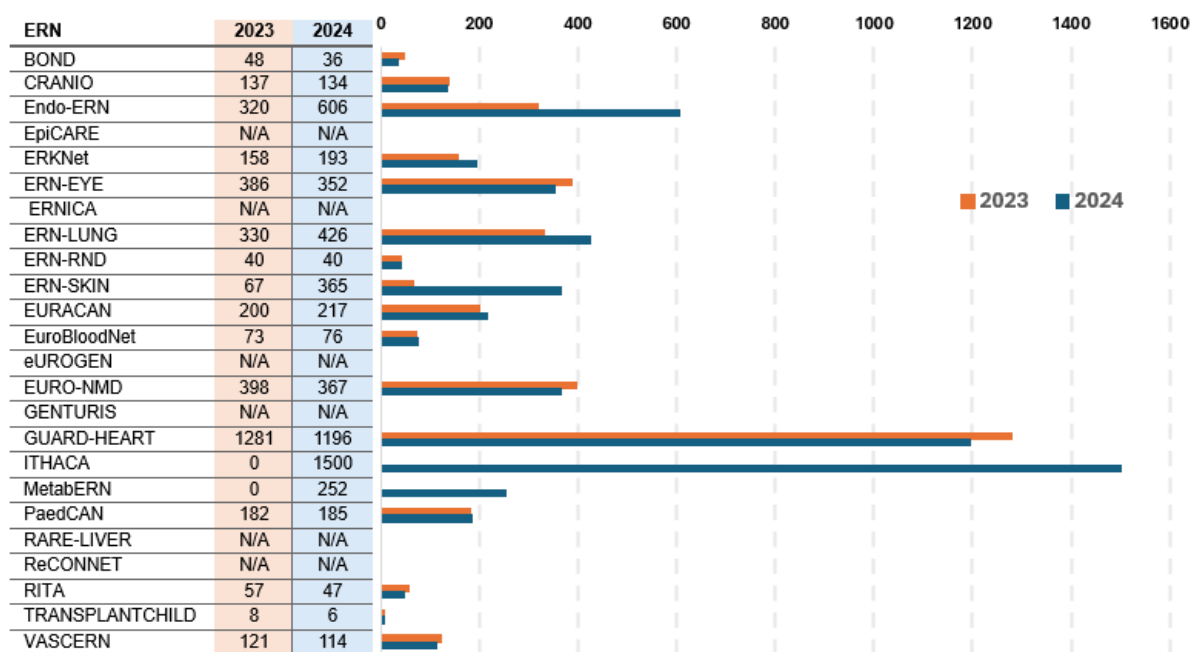
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	3	3	6
Members	6	19	3	28
Total	6	22	6	34
Percentage	17,6%	64,8%	17,6%	

Ireland

ERN Coordination Role	0		
ERN Membership	18/24		
Number of Hospitals	5		
Number of Clinical Centres	18	MEMBERS 18 (100%)	AFFILIATED PARTNERS 0 (0%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



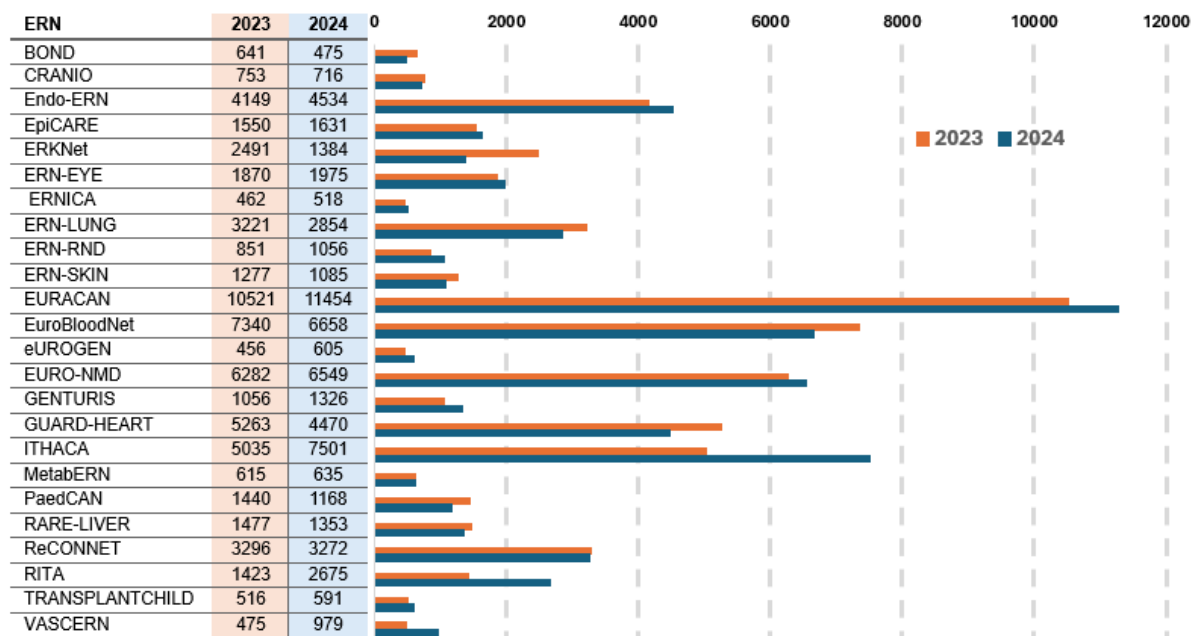
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	-	-	-
Members	3	14	1	18
Total	3	14	1	18
Percentage	16,6%	77,8%	5,6%	

Italy

ERN Coordination Role	3 (BOND; METABERN; RECONNET)		
ERN Membership	24/24		
Number of Hospitals	83		
Number of Clinical Centres	325	MEMBERS 325 (100%)	AFFILIATED PARTNERS 0 (0%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



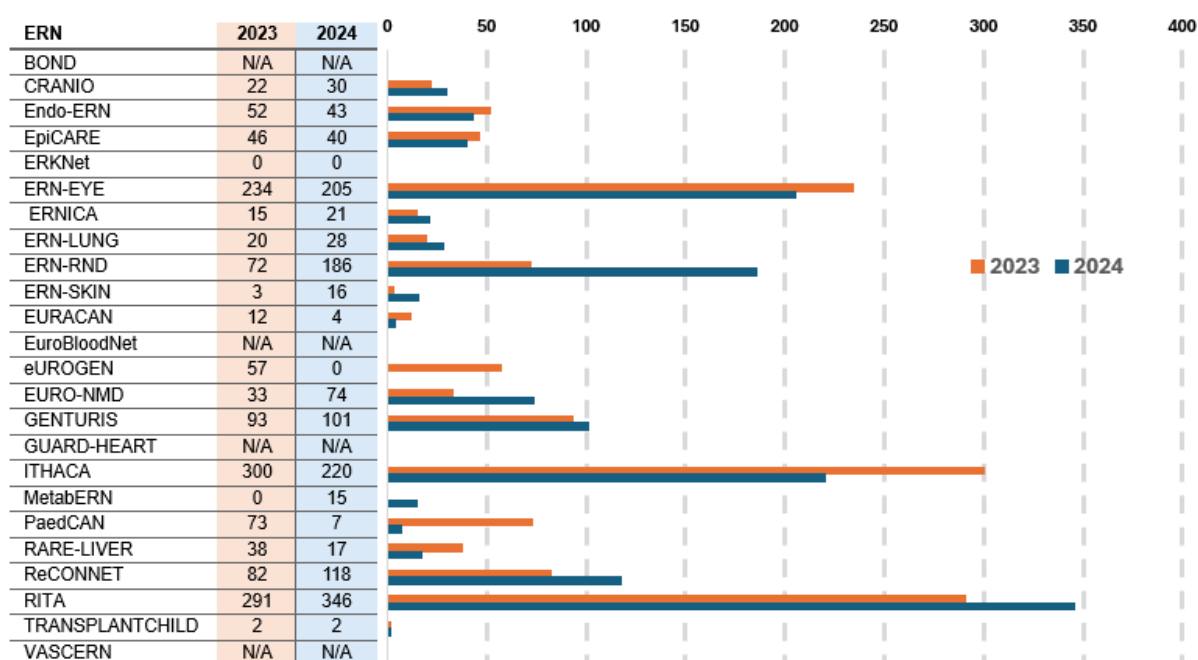
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	-	-	-
Members	114	170	41	325
Total	114	170	41	325
Percentage	35,1%	52,3%	12,6%	

Latvia

ERN Coordination Role	0		
ERN Membership	20/24		
Number of Hospitals	4		
Number of Clinical Centres	24	MEMBERS 6 (25%)	AFFILIATED PARTNERS 18 (75%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



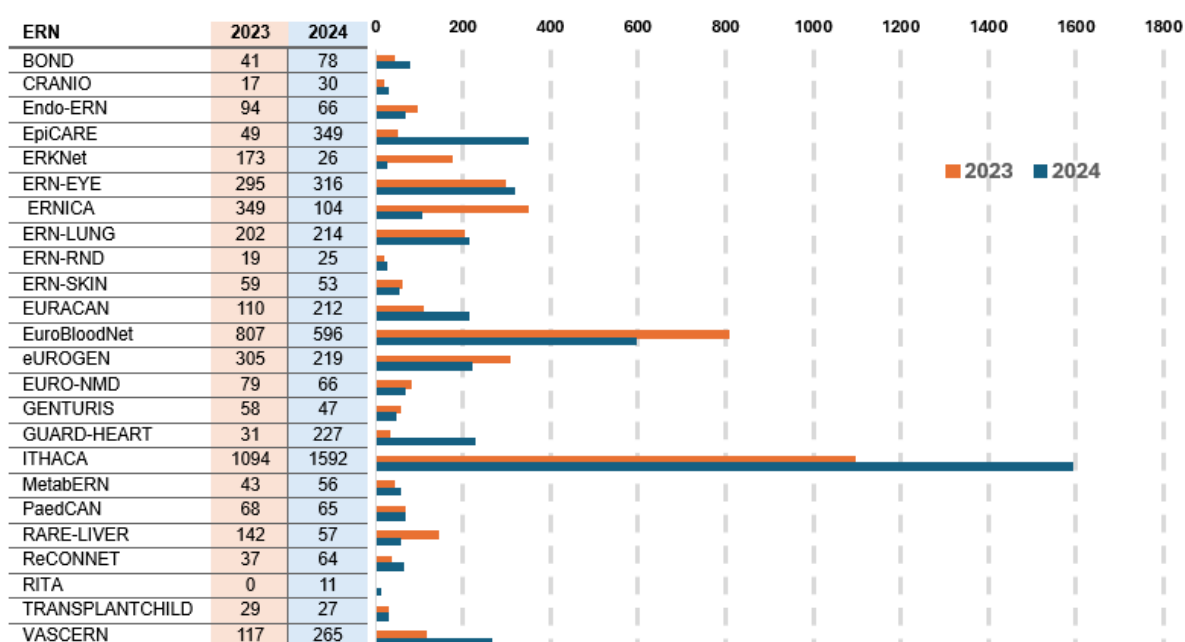
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	13	-	5	18
Members	4	-	2	6
Total	17	-	7	24
Percentage	70,8%	-	29,2%	

Lithuania

ERN Coordination Role	0		
ERN Membership	24/24		
Number of Hospitals	2		
Number of Clinical Centres	31	MEMBERS 17 (55%)	AFFILIATED PARTNERS 14 (45%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



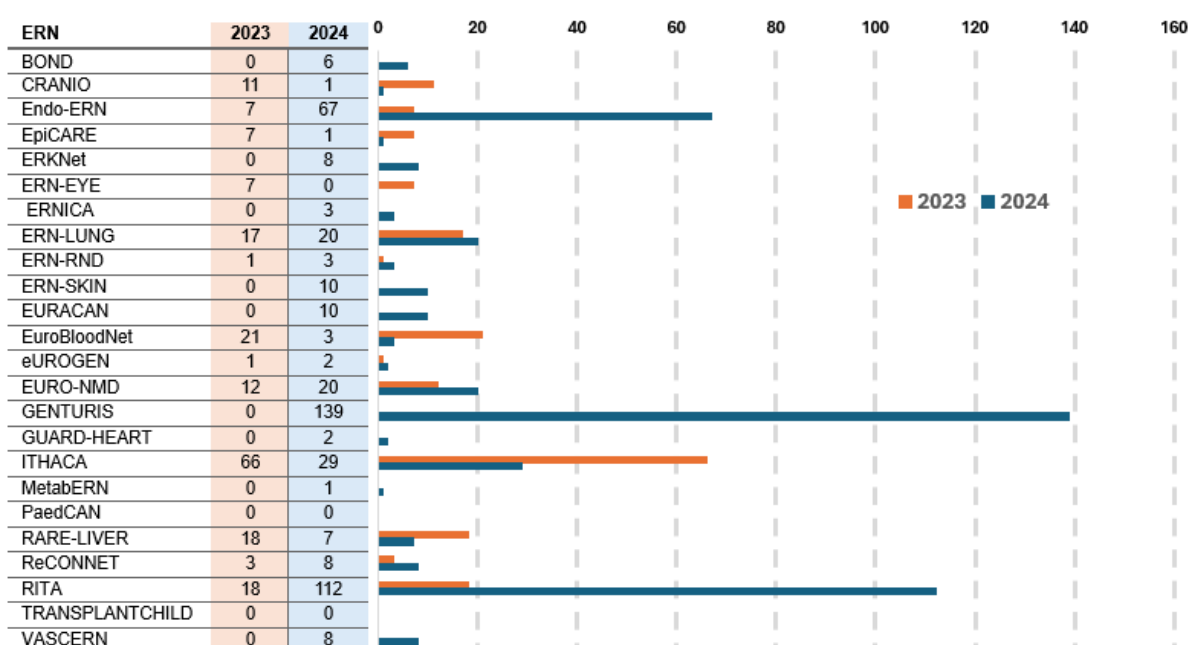
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	10	2	2	14
Members	8	7	2	17
Total	18	9	4	31
Percentage	58,1%	29%	12,9%	

Luxembourg

ERN Coordination Role	0		
ERN Membership	24/24		
Number of Hospitals	1		
Number of Clinical Centres	24	MEMBERS 1 (4,2%)	AFFILIATED PARTNERS 23 (95,8%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



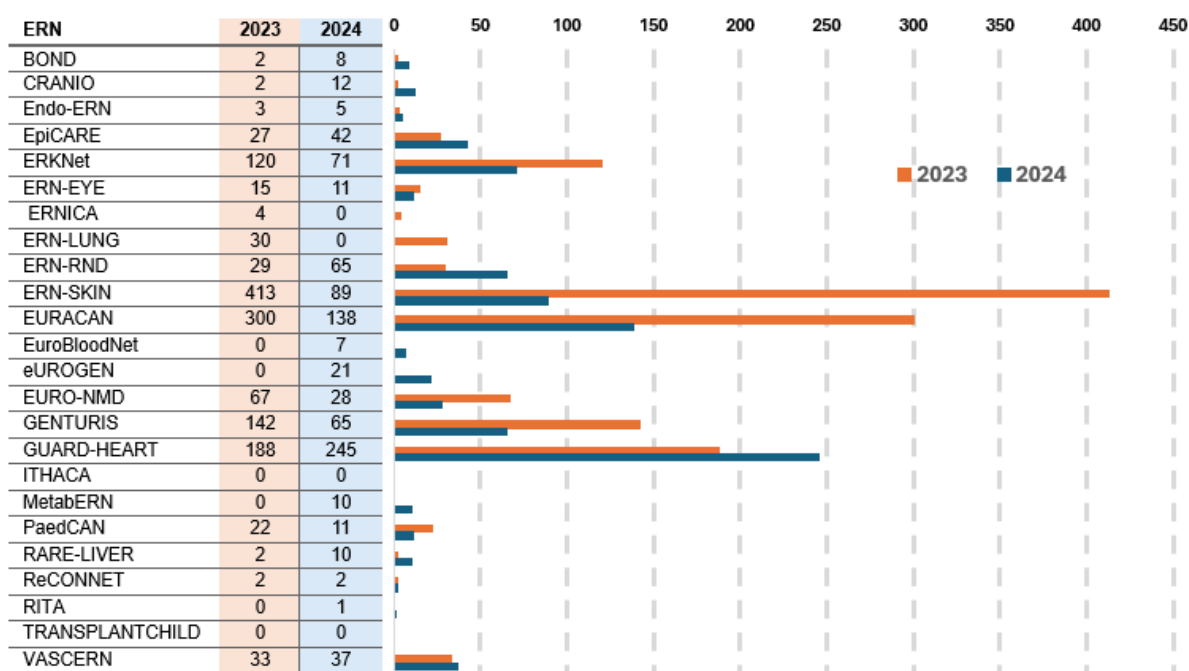
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	22	1		23
Members	1	-	-	1
Total	23	1	-	24
Percentage	95,8%	4,2%		

Malta

ERN Coordination Role	0		
ERN Membership	24/24		
Number of Hospitals	1		
Number of Clinical Centres	24	MEMBERS 0 (0%)	AFFILIATED PARTNERS 24 (100%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



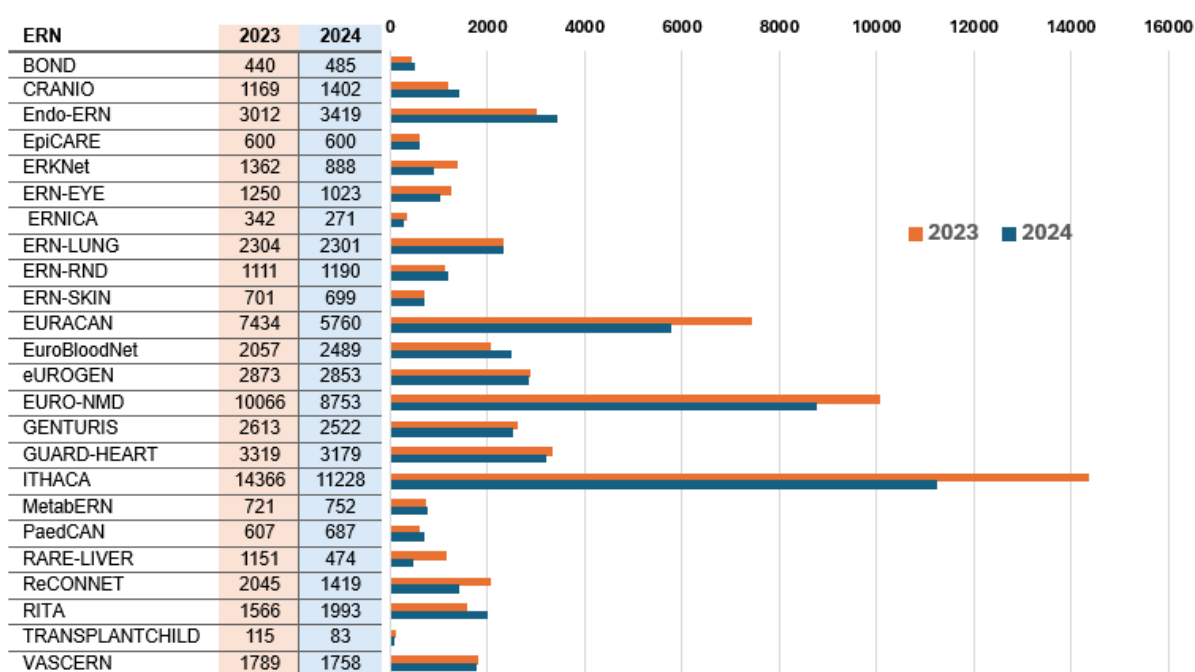
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	13	1	10	24
Members	-	-	-	-
Total	13	1	10	24
Percentage	54,2%	4,2%	41,6%	

The Netherlands

ERN Coordination Role	7 (CRANIO; ENDO-ERN; ERNICA; EUROGEN; GENTURIS; GUARD-HEART; RITA)		
ERN Membership	24/24		
Number of Hospitals	14		
Number of Clinical Centres	123	MEMBERS 123 (100%)	AFFILIATED PARTNERS 0 (0%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



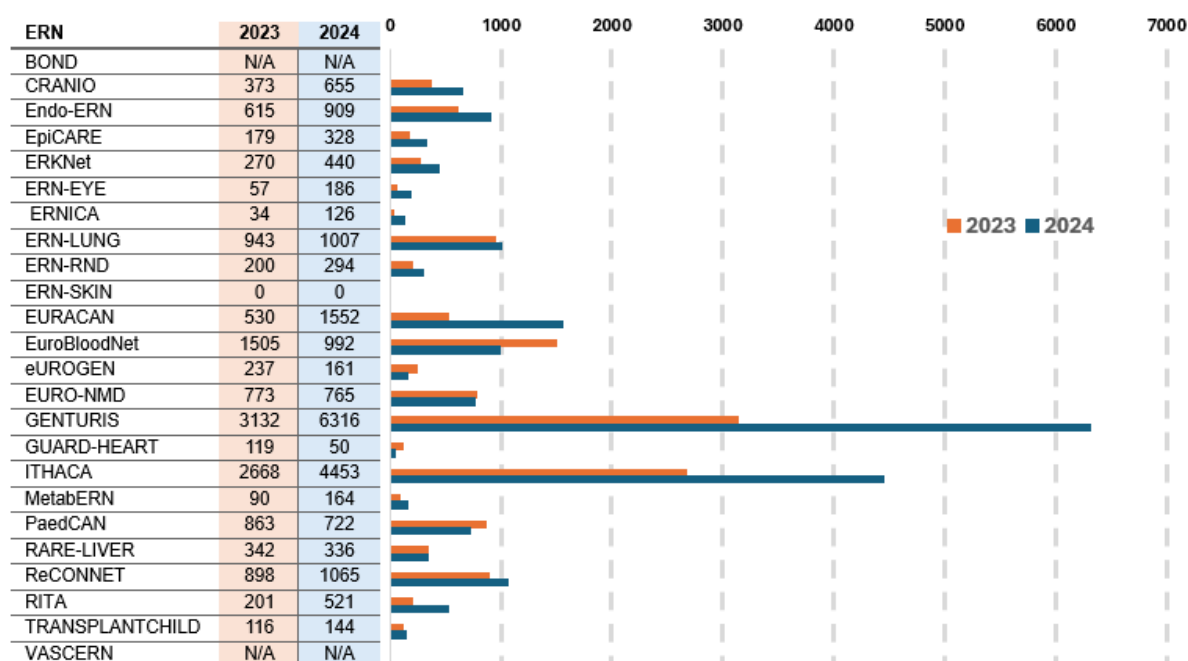
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	-	-	
Members	48	60	15	123
Total	48	60	15	123
Percentage	39%	48,8%	12,2%	

Poland

ERN Coordination Role	0		
ERN Membership	21/24		
Number of Hospitals	24		
Number of Clinical Centres	45	MEMBERS 44 (98%)	AFFILIATED PARTNERS 1 (2%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



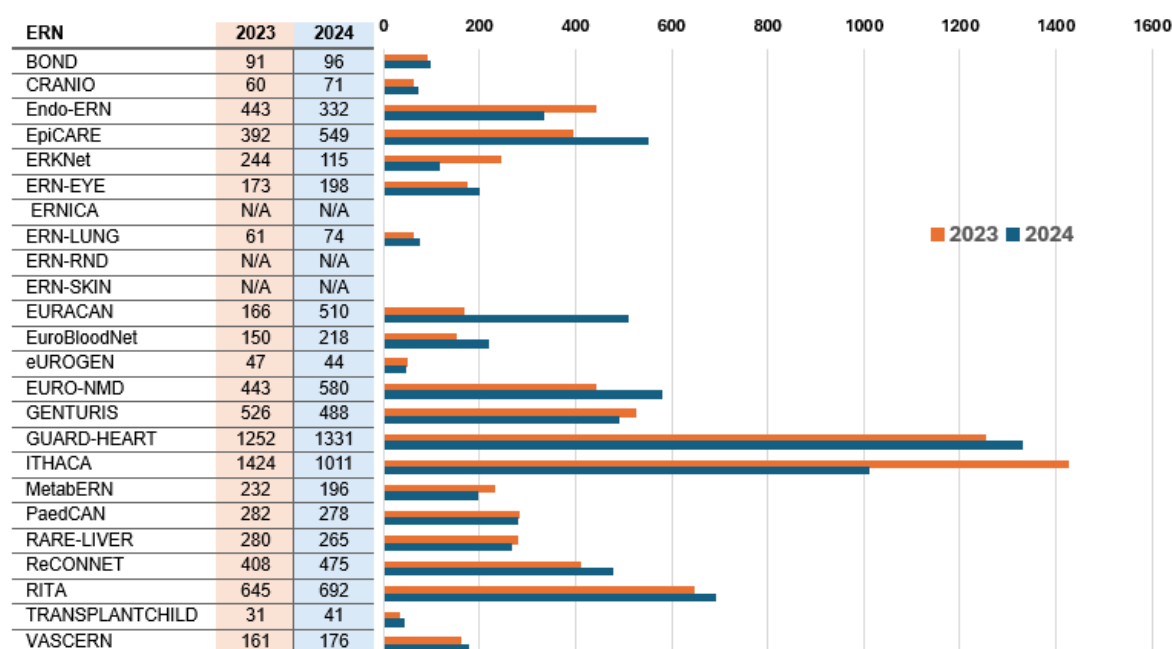
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	1	-	1
Members	22	21	2	44
Total	22	21	2	45
Percentage	48,9%	46,7%	4,4%	

Portugal

ERN Coordination Role	0		
ERN Membership	21/24		
Number of Hospitals	11		
Number of Clinical Centres	48	MEMBERS 48 (100%)	AFFILIATED PARTNERS 0 (0%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



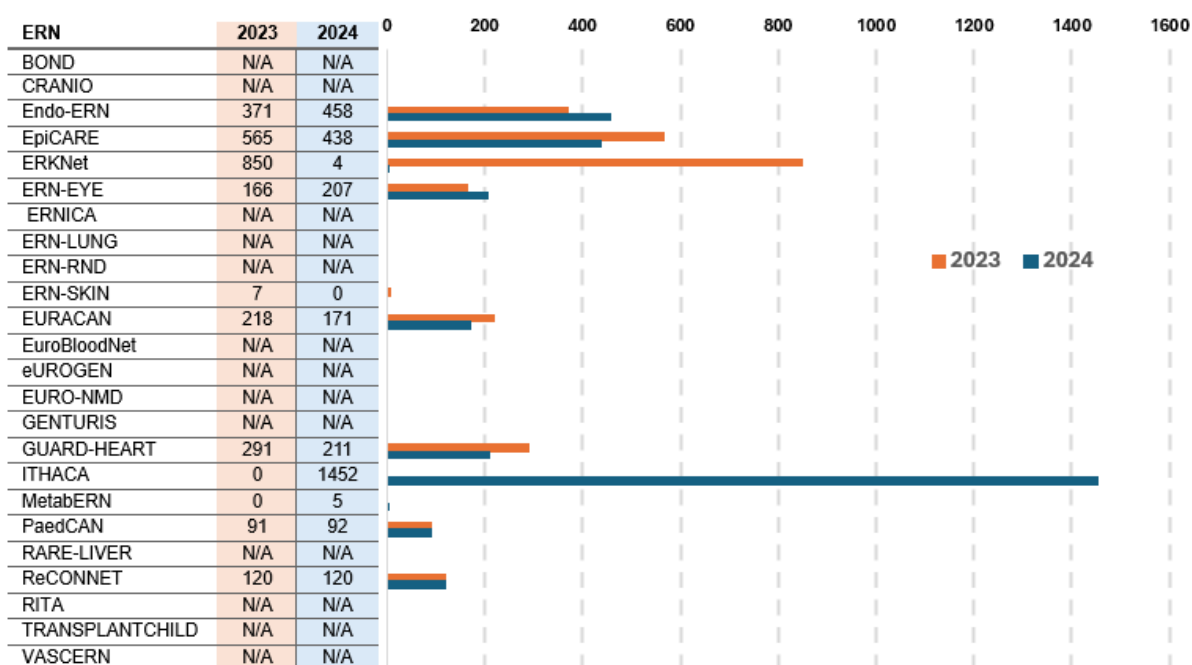
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	-	-	-
Members	21	20	7	48
Total	21	20	7	48
Percentage	43,7%	41,7%	14,6%	

Romania

ERN Coordination Role	0		
ERN Membership	11/24		
Number of Hospitals	10		
Number of Clinical Centres	15	MEMBERS 13 (87%)	AFFILIATED PARTNERS 2 (13%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



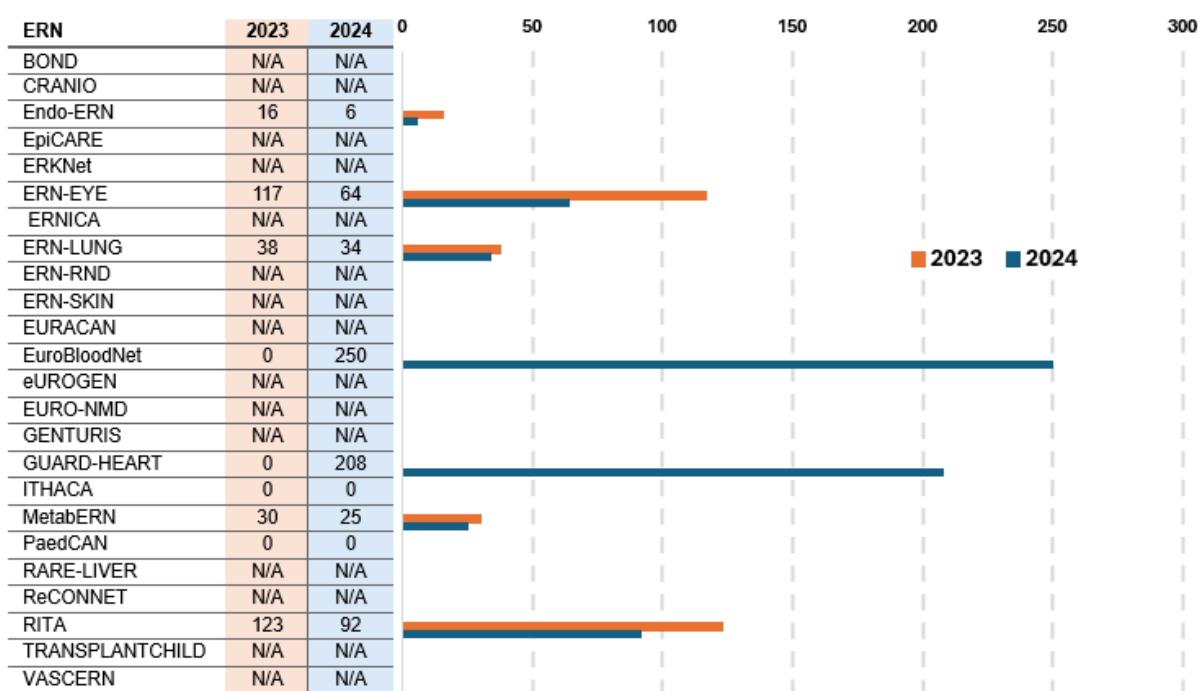
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	1	1	2
Members	4	7	2	13
Total	4	8	3	15
Percentage	26,7%	53,3%	20%	

Slovakia

ERN Coordination Role	0		
ERN Membership	9/24		
Number of Hospitals	4		
Number of Clinical Centres	10	MEMBERS 5 (42%)	AFFILIATED PARTNERS 5 (58%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



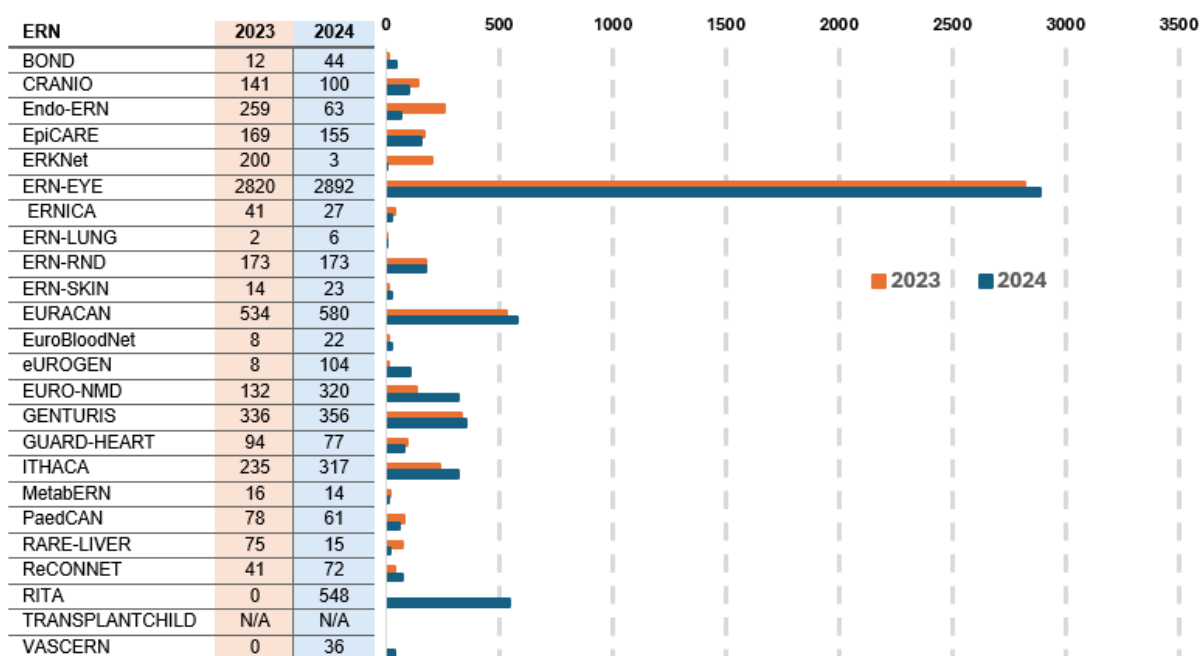
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	3	4	7
Members	2	2	1	5
Total	2	5	5	12
Percentage	17%	42%	42%	

Slovenia

ERN Coordination Role	0		
ERN Membership	23/24		
Number of Hospitals	3		
Number of Clinical Centres	23	MEMBERS 13 (54%)	AFFILIATED PARTNERS 10 (46%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



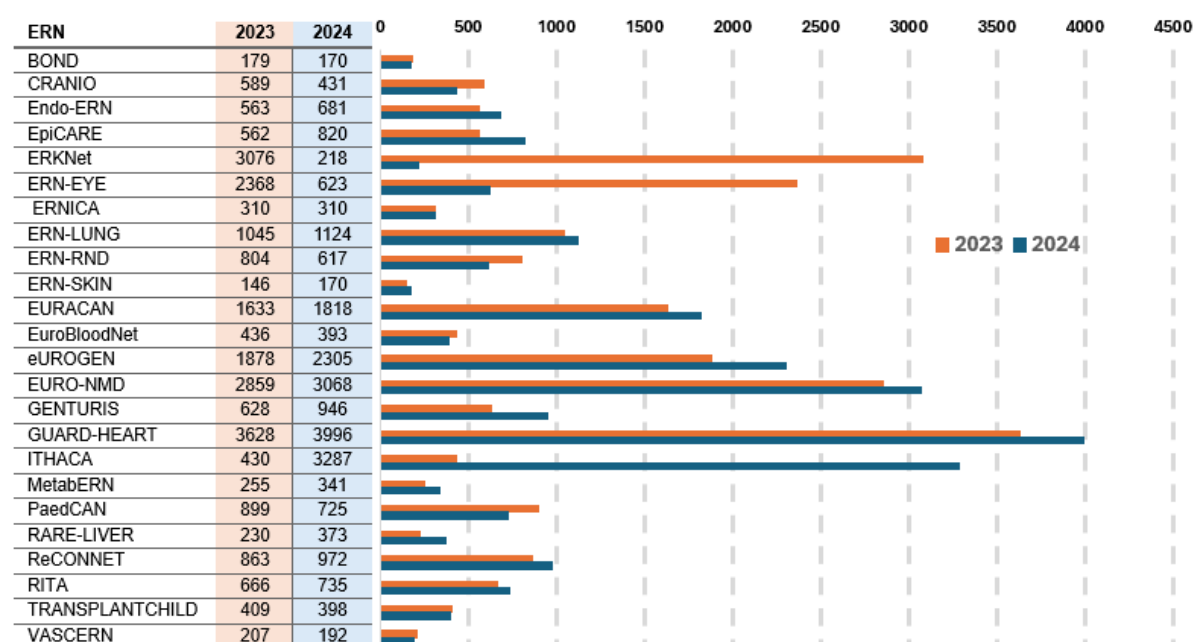
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	7	3	1	11
Members	4	7	2	13
Total	11	10	3	24
Percentage	45,8%	41,7%	12,5%	

Spain

ERN Coordination Role	2 (EPICARE; TRANSPLANTCHILD)		
ERN Membership	24/24		
Number of Hospitals	24		
Number of Clinical Centres	110	MEMBERS 110 (100%)	AFFILIATED PARTNERS 0 (0%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



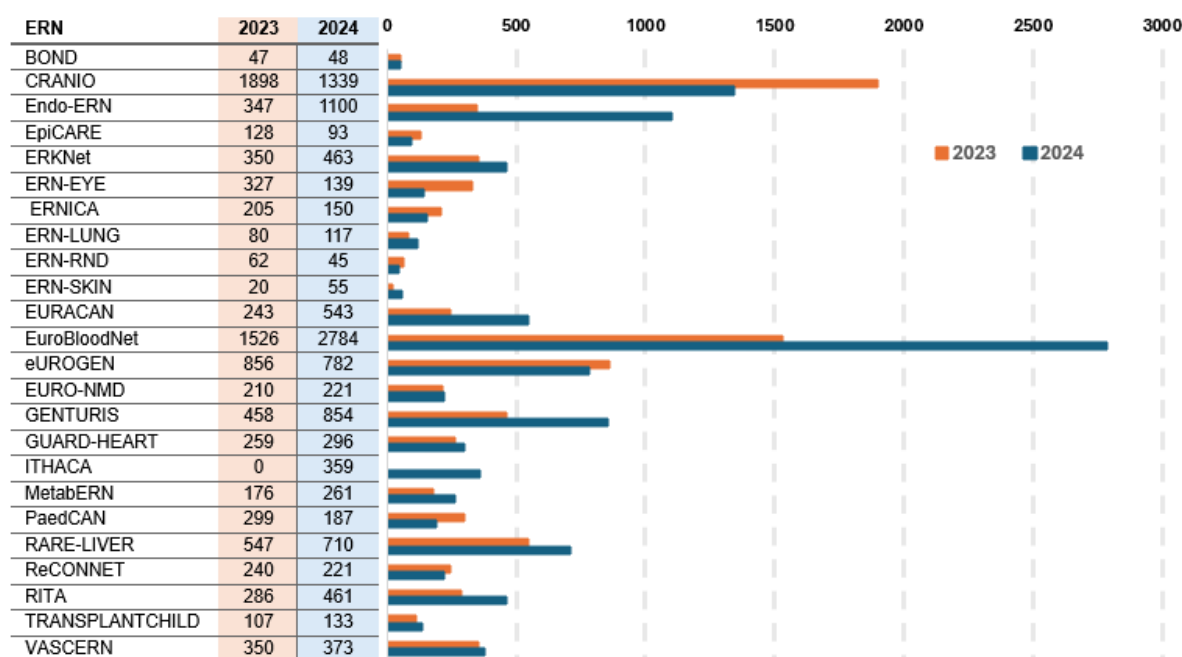
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	-	-	-
Members	74	27	9	110
Total	74	27	9	110
Percentage	67,3%	24,5%	8,2%	

Sweden

ERN Coordination Role	0		
ERN Membership	24/24		
Number of Hospitals	6		
Number of Clinical Centres	45	MEMBERS 45 (100%)	AFFILIATED PARTNERS 0 (0%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



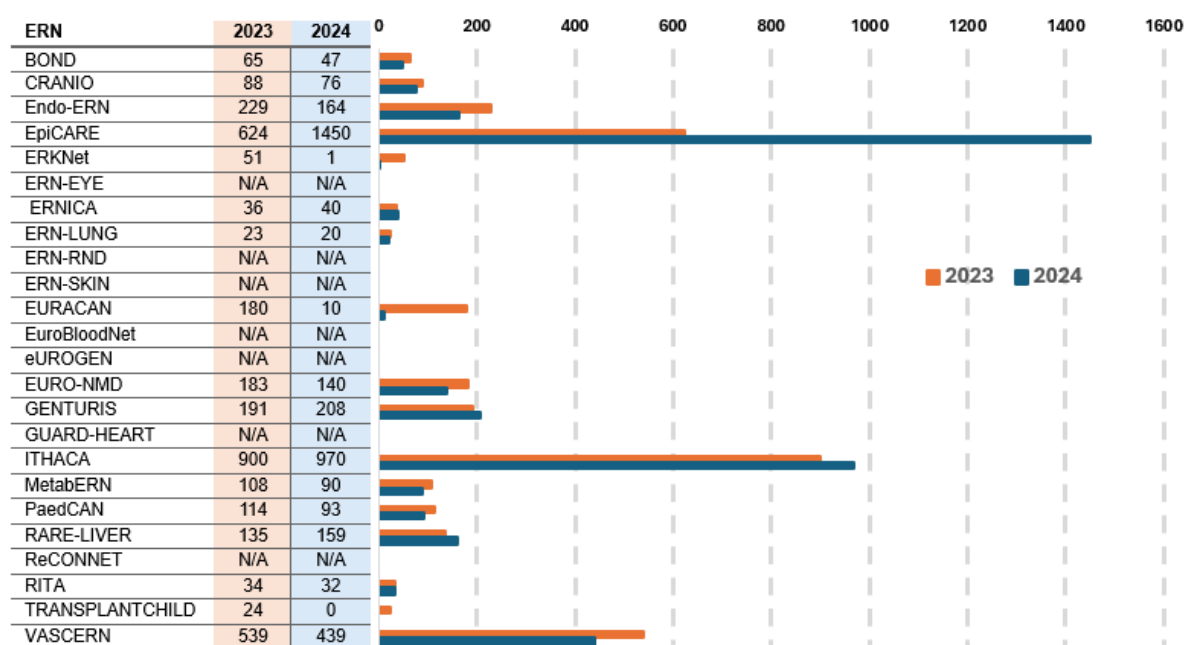
Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	-	-	-
Members	4	40	1	45
Total	4	40	1	45
Percentage	8,9%	88,9%	2,2%	

Norway

ERN Coordination Role	0		
ERN Membership	17/24		
Number of Hospitals	3		
Number of Clinical Centres	20	MEMBERS 14 (70%)	AFFILIATED PARTNERS 6 (30%)

Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN



Mapping of the use of orphacodes

Membership Type	Yes	No	N/A	Number of Clinical Centres
Affiliated Partners	-	4	2	6
Members	8	4	2	14
Total	8	8	4	20
Percentage	40%	40%	20%	

Conclusion

This first monitoring report provides an overall picture of ERN activities according to their areas of work as well as a Member State perspective with the inclusion of country profiles. The inclusion of data from 2023 provides a view into potential trends. This allows, for example, to see the growth across all ERNs of new patients referred to the HCPs or the increased use of orphacodes across clinical centres.

Altogether, the compilation of these indicators shows the meaningfulness of the activities and the impact of the Networks on improving the life of patients living with rare diseases.

Further insights will therefore come from the future exercises. With growing numbers of new patients, increased usage of the CPMS, widely accessible and attended training and education activities, the ERNs are demonstrating their concrete added value for patients and families affected by rare diseases.

It is also important to highlight that the 24 ERNs have their own specificities. For example, an ERN with a larger disease area or number of centres may register a larger number of new patients if compared to an ERN with a more limited disease scope or number of centres. Therefore, any comparative analysis is difficult to run and would not necessarily have meaningful interpretations.

In future editions of this report, efforts will be taken to address the data limitations highlighted above. This approach will be pursued in coordination with the ERNs and the Member States in the years to come so to be able to further analyse the networks, their activities and impact for patients and families with rare diseases.

