

ERIN PaedCan
5-year
evaluation

Ruth Ladenstein
ePAG Steering Committee Annual online
meeting
November 13th 2023

EXPECTATIONS TO ERNs

- The 2011 Directive on Patients' Rights in Cross-border Healthcare:**
 - enables patients to be reimbursed for treatment in another EU Member State
 - Implemented in 2013 EU Member States in 2013
- EU Health Programme:**
 - Call for ERNs in 2016
 - The first 24 European Reference Networks started their activities in 2017.
- Expectations**
 - Consolidating knowledge and expertise scattered across countries
 - Providing access to a much larger pool of expertise.
 - Better chances for patients to receive an accurate diagnosis and advice on the best treatment

EACH YEAR THOUSANDS OF PATIENTS WILL BE HELPED BY ERNs

ERIN PaedCan Mission

- Reduce inequalities** across Member States by **enabling access to up-to-date diagnostics and treatments** by facilitating the exchange of expertise and knowledge.
- Ensure that **information travels** rather than the patient through implementation of **Virtual Tumour Boards**.
- Unite** the best specialists across Europe **through cross-border healthcare** to tackle complex or rare cancer conditions that require highly specialised interventions and a concentration of knowledge and resources.

ERIN PaedCan General Assembly, 29-30.06.2023

ERIN PaedCan – on of the largest networks

Nr.	ERN	Number of FMs and Aps	Countries represented
1	ENDO	109	98 11 28
2	ERIN PaedCan	92	81 21 28
3	ERN Lung	90	79 11 25
4	EURACAN	105	97 8 26
5	ERN EuroshockNet	108	96 7 24
6	METABERN	92	86 6 27
7	EPICARE	51	39 12 24
8	ERN EURO-NMD	84	76 8 25
9	ERN Skin	59	55 4 21
10	ERNKnet	74	65 9 24
11	ERN IHACA	73	67 6 26
12	ERN EYE	60	52 8 24
13	ERN-RND	69	64 5 24
14	ERN RARE-LIVER	63	55 8 23
15	ERN GUARD-HEART	54	45 9 23
16	ERN RITA	74	62 12 25
17	ERNICA	54	42 12 21
18	ERN GENTURIS	53	45 8 23
19	ERN Bond	57	47 20 20
20	ERN eUROGEN	59	52 7 20
21	ERN Cranio	42	35 7 21
22	ERN Transplantchild	40	33 7 21
23	ERN Reconnet	66	57 9 23
24	VASCERN	46	40 6 19
Average:		70	61 8 24

***FM=Full member, AP= Affiliated Partner**

	Austria	Belgium	Bulgaria	Croatia	Cyprus	Czech Republic	Denmark	Estonia	Finland	France	Germany	Greece	Hungary	Ireland	Italy	Latvia	Lithuania	Luxembourg	Malta	Netherlands	Norway	Poland	Portugal	Romania	Slovakia	Slovenia	Spain	Sweden	Grand Total
AFFILIATED PARTNERS																													
FULL MEMBERS SINCE 2017	1	3	1	3	1	2	2	2	3	7	10	1	1	9	1	1	1	1	1	1	1	3	2	2	1	1	4	21	
New FULL MEMBERS since 2022	1	1	1	1	1	1	1	1	1	10	1	1	1	1	3	1	1	1	1	1	1	3	1	1	1	1	2	29	
Grand Total	1	4	1	3	1	2	2	2	4	7	20	1	2	1	12	1	1	1	1	2	1	6	3	2	1	1	6	50	

ERIN PaedCan Member Status across Europe

New FULL MEMBERS since 2022: 29 (32%)

AFFILIATED PARTNERS: 11 (12%)

EVALUATED

FULL MEMBERS SINCE 2017: 52 (56%)

Cross Border Health Care Activity of ERIN PaedCan members

ERIN PaedCan
Number of patients and cross-border referrals, and its proportion by year

Year	2016	2017	2018	2019	2020	2021	2022
Proportion of CB referrals	9%	13%	16%	23%	9%	10%	15%
Cross-border referrals per year	556	842	1130	1637	582	695	2,025
Total number of patients per year	5,857	6,315	7,057	7,057	6,146	6,778	10,393

ERIN PaedCan's Work- Plan Year 1-5 Objectives

2017	2018	2019	2020	2021
01: Roadmap development (ESCP)				
02: Patient and Survivor Organisation (PASO) integration				
03: Virtual Tumour Board				
04: Twinning Programs				
05: Survivorship Passport Roll-Out				
06: Knowledge sharing and dissemination				
07: Very Rare Tumours integration				
08: Best Practice Sharing				
09: e-Training and capacity building				

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5-Year Evaluation

- The European Commission's aim:**
 - to contribute to the continuous betterment and growth of ERNs, improving and demonstrating their value towards providing highly specialized quality cross-border healthcare for persons with rare or low-prevalence complex conditions
- Methodology and Evaluation Scheme**
 AMEQIS = integrated Assessment, Monitoring, Evaluation and Quality Improvement System
 - developed and proposed by Avedis Donabedian Foundation (FAD) and the Netherlands Institute for Health Services Research (NIVEL), namely the AMEQIS consortium, under a service contract with the Health and Digital Executive Agency (HaDEA) of the European Commission

5-Year Evaluation

Look back at the initial mission, aims and plans of the ERN:

- Did ERNs achieve their 5-year goals? (network structure, budgets, strategy)
- How well are European countries and different diseases covered?
- Are the conditions created to provide better care to patients? (stimulation of multidisciplinary teamwork, patient participation in the network, in research activities and guideline development)

Look at ERN impact:

- How many patients have been helped?
- How have ERN clinical guidelines changed clinical practice?
- How satisfied are clinical teams with what the ERN brings them?

Look at ERN activities:

- Have education material / trainings been developed?
- Is knowledge shared and disseminated (publications, participation in clinical trials)
- Do members collaborate?

ERIN Evaluation Experience

- Complicated and lengthy guidelines (281 pages):**
 - Evaluation Toolbox: 152 pages,
 - Evaluation Manual: 34 pages,
 - FAQ: 18 pages,
 - OETI guide: 17 pages,
 - Comments and Improvement Guidelines: 14 pages,
 - Acknowledgement Guideline: 8+6 pages,
 - IP examples: 24 pages,
 - On-site audit guide: 8 pages
- Evaluation Portal not very user friendly**
- Self-evaluation form could not handle 'hubs of coordination' (i.e. HCP involved in more than 1 ERN)**
- ERIN Evaluation Team very friendly and helpful; responses always quick**
- Audit Team very helpful and friendly**

Self-evaluation Form / Section A, B and C

FORM / Section A – Word Document Template

FORM / Section B – Evaluation Portal / "Information"


Section C – Evaluation Portal / "Information" -> supporting documents wherever requested

ERIN PaedCan's Insights

- The ERN Evaluation**
 - the implementation of the 5-Years' Work Plan
 - the quality of deliverables of the network
 - the outreach of the network and its strategy to reach all patients concerned
- MS-level evaluation/certification/audits shall ensure:**
 - The quality of patient care
 - The quality of the multidisciplinary staff
 - And in general: the Fulfilment of the prerequisites of the national designation

ERN PaedCan's efforts:

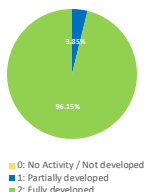
- Onboarding started almost 2 years earlier, regular updates on AMEQIS in the GA meetings
- Templates (partly prefilled / with detailed guidance) and guidelines circulated, shared OneDrive Folder set up with all of them
- Dedicated session in the December 2022 GA meeting
- Dedicated online meetings helping the individual HCPs filling in their forms
- 1000+ emails



1000 conversations selected

OUTCOME for ERN PaedCan: a SATISFACTORY Result

ERN PaedCan compliance with the Criteria



ERN PaedCan Rating for all and core ME per thematic area

Thematic Area	Core ME	All ME
1. Governance and coordination	1.9	1.82
2. Clinical care	2	2
3. Quality and patient safety	1.67	2
4. Patient centred care	2	2
5. Contribution to Research	2	2
6. Education and Training	2	2
7. Networking and Dissemination	2	2

ERN PaedCan's Strengths


- Governance and coordination:** organisational approach that enables close collaboration between parents' and patients' representatives, professional societies and members the network.
- Clinical care:** development of 10 ESCPs (+ 14 ESCPs after evaluation).
- Patient centred care:** Parents' and patients' representatives have an active role in guidelines revision process, decision making and policy development. They also play a key role in communication and dissemination.
- Education and training:** Educational program including CME accredited webinars.
- Contribution to research:** Hubs of coordination providing advisory functions in Tumour Boards.

Areas for improvement

- Clinical care:** Implementation of internal assessment of HCPs' contribution to the network.
- Contribution to research:** foster strong Twinning activities with great added value such as the TREL project.
- Networking and dissemination:** ensure the increased use of CPMS for cross-border patient care advice.

HCPs evaluation results

- 52 HCPs members of ERN PaedCan were evaluated
- 50 HCPs completed the evaluation process
 - 2 HCPs didn't started the evaluation process. Their membership has been terminated, as per the BoMS decision. (Full EU + Norway coverage remains intact)



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Outcomes and impact

- Integrating an evaluation system that measures the ERN impact
- Increasing accountability of the ERNs
- Improving patient-centred care and clinical outcomes
- Opportunities for benchmarking of common indicators
- Instituting a harmonized application process of the ERNs
- Reinforcing ERNs with a robust quality improvement process
- Opportunities for improving efficiency of the ERN

ERN PaedCan General Assembly, 23.11.2022



Towards a brighter future for our children with cancer

THANK YOU!
ERNPaedCan@ccri.at



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