



 **Network**
Paediatric Cancer
(ERN PaedCan)

What is ERN PaedCan?

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Moderator :
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1 ERN Developments

- The 2011 Directive on Patients' Rights in Cross-border Healthcare:
 - enables patients to be reimbursed for treatment in another EU Member State
 - The Directive became law in EU Member States in 2013 and emphasises **the value of eHealth** and the **importance of interoperability** in national health IT systems in facilitating information sharing.
- EU Health Programme:
 - **Call for ERNs in 2016**
 - **The first 24 European Reference Networks started their activities in 2017.**

A directive is a legal act adopted by the EU institutions [...], is binding as to the result to be achieved.

2 ERN Developments

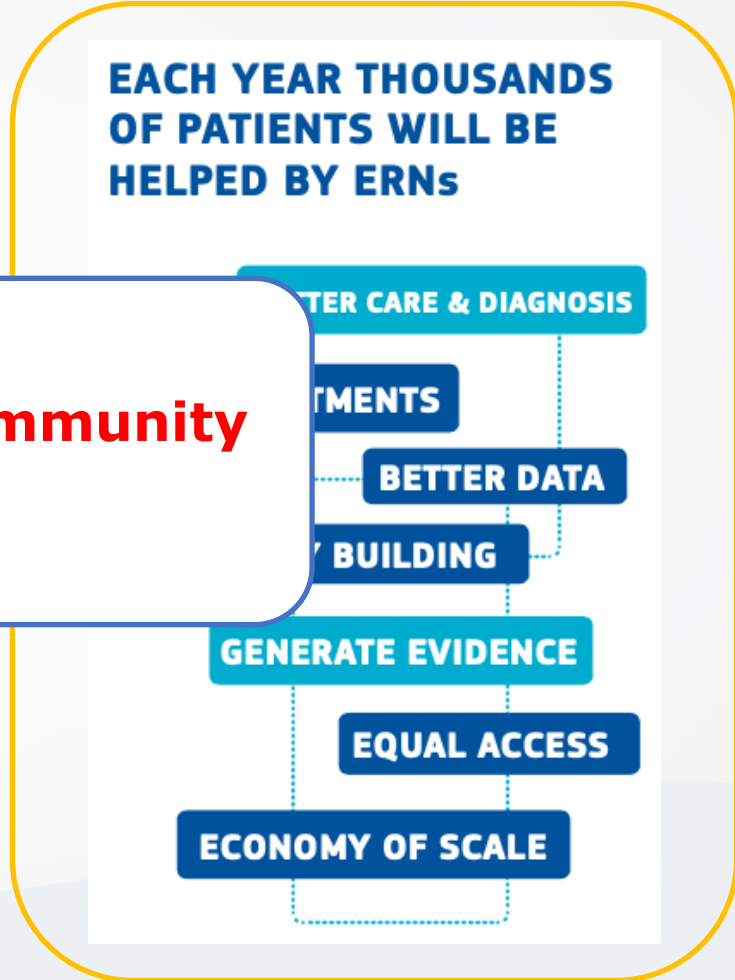
- Shortcomings:
 - S2 and compensation scheme between member states (mainly concerning clinical trials)

3 Expectations to ERNs



- Consolidating knowledge and expertise scattered across countries
- Providing access to
- Better chances for and advice on the

But the childhood cancer community is different

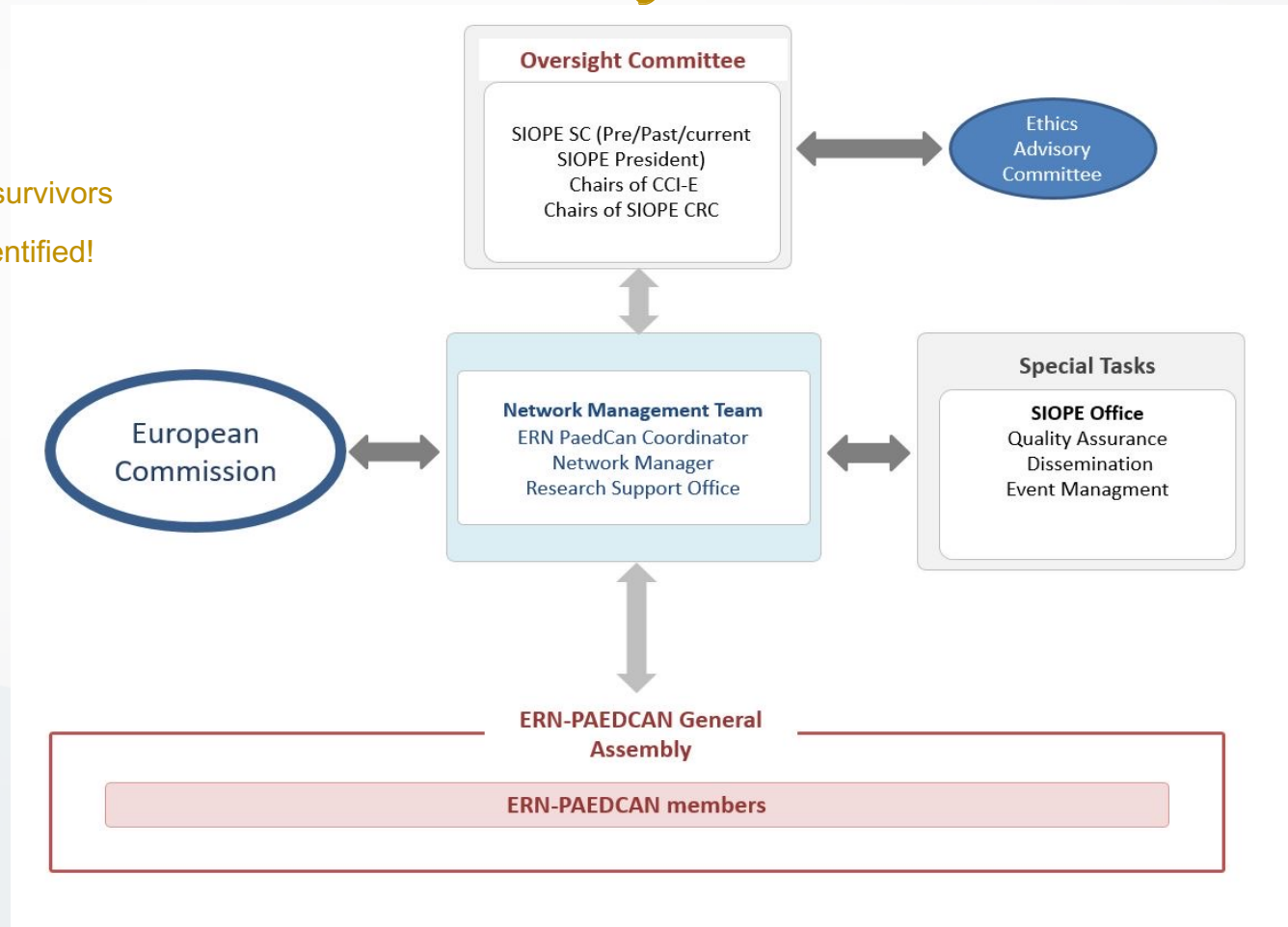


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ERN PaedCan Oversight Committee: A perfect structure to drive the ESCP development process together with and for the European PO Community



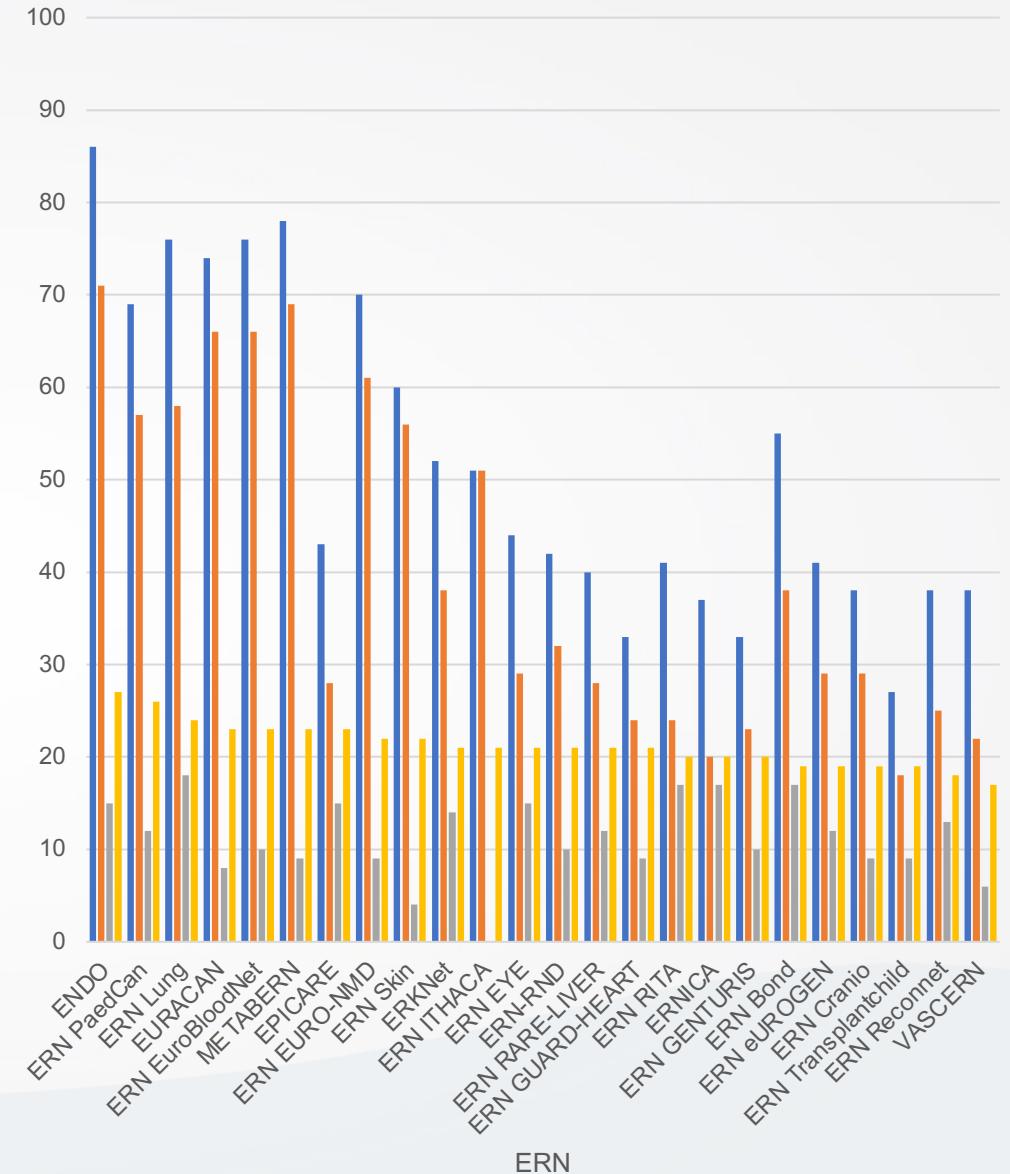
...provides views of parents and survivors
...volunteers for ESCP project identified!



Nr.	ERN	Number of FMs and Aps	FMs	Aps	Countries represented
1	ENDO	86	71	15	27
2	ERN PaedCan	69	57	12	26
3	ERN Lung	76	58	18	24
4	EURACAN	74	66	8	23
5	ERN EuroBloodNet	76	66	10	23
6	METABERN	78	69	9	23
7	EPICARE	43	28	15	23
8	ERN EURO-NMD	70	61	9	22
9	ERN Skin	60	56	4	22
10	ERKNet	52	38	14	21
11	ERN ITHACA	51	51	0	21
12	ERN EYE	44	29	15	21
13	ERN-RND	42	32	10	21
14	ERN RARE-LIVER	40	28	12	21
15	ERN GUARD-HEART	33	24	9	21
16	ERN RITA	41	24	17	20
17	ERNICA	37	20	17	20
18	ERN GENTURIS	33	23	10	20
19	ERN Bond	55	38	17	19
20	ERN eUROGEN	41	29	12	19
21	ERN Cranio	38	29	9	19
22	ERN Transplantchild	27	18	9	19
23	ERN Reconnet	38	25	13	18
24	VASCERN	38	22	6	17
TOTAL:		1232	962	270	-
Average:		52	40	11	21

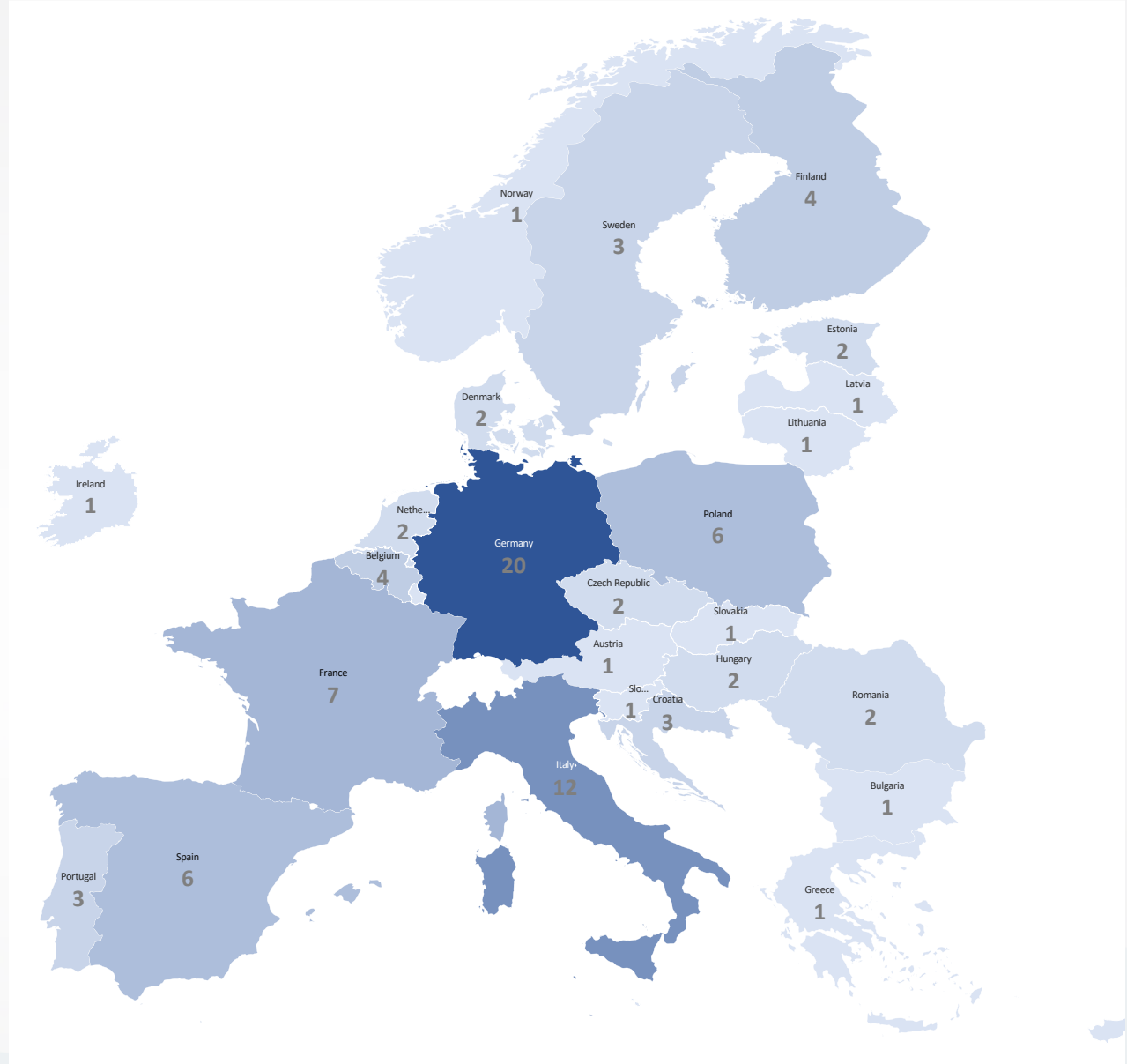
*FM=Full member, AP= Affiliated Partner

Membership overview





	Current member	Ex-member
Austria	1	
Belgium	4	
Bulgaria	1	
Croatia	3	
Cyprus	1	
Czech Republic	2	
Denmark	2	
Estonia	2	
Finland	4	
France	7	
Germany	20	
Greece	1	
Hungary	2	
Ireland	1	
Italy	12	
Latvia	1	
Lithuania	1	
Luxembourg	1	
Malta	1	
Netherlands	2	1
Norway	1	
Poland	6	1
Portugal	3	
Romania	2	
Slovakia	1	1
Slovenia	1	
Spain	6	
Sweden	3	
United Kingdom		3
TOTAL:	92	6



As of 01.01.2022: **92 members from, 81 Full Members** (from 20 countries), **11 Affiliated Partners** (from 7 countries)
27 EU MS and Norway
(full EU coverage)

7 Affiliated Partners

1	Bulgaria	ANCs	Pediatric Oncohematology Department, University Hospital "Tsaritsa Johanna-ISUL"
2	Croatia	ANCs	Division of Pediatric Hematology and Oncology, Centre of Reference for Pediatric Hematology and Oncology Ministry of Health Republic of Croatia, Department of Pediatrics, University Hospital Center Zagreb, University of Zagreb, School of Medicine
3	Croatia	ANCs	Children's University Hospital Zagreb, Division of Paediatrics Oncology and Haematology
4	Croatia	ANCs	DIVISION FOR PEDIATRIC HAEMATOLOGY AND ONCOLOGY, UNIVERSITY DEPARTMENT OF PEDIATRICS, UNIVERSITY HOSPITAL CENTRE RIJEKA, CROATIA
5	Cyprus	ANCs	Pediatric Oncology/Hematology Clinic Archbishop Makarios III Hospital
6	Estonia	ANCs	Tallin Children's Hospital
7	Estonia	ANCs	Tartu University Hospital
8	Luxembourg	HUBs	Centre Hospitalier du Luxembourg
9	Malta	HUBs	Mater Dei Hospital
10	Romania	ANCs	Institutul Oncologic "Prof. Dr. Alexandru Trestioreanu" Bucuresti
11	Romania	ANCs	Institutul Clinic Fundeni Bucuresti
12	Slovakia	ANCs	National Institute of Children's Diseases, Comenius University in Bratislava, Faculty of Medicine, Department of Paediatric Haematology and Oncology (as of 01.01.2022 Full Member!)

ANCs = Associated National Center; HUBs = National Coordination Hubs

8 ERN PaedCan: Mission, Vision and Key Benefits

- MISSION:

- Reduce inequalities of childhood cancer outcomes across Member States – cross-border healthcare with Virtual Tumour Boards (VTBs)

- VISION:

- Equal and possible best paediatric cancer care and outcomes no matter where in Europe children live

- Key Benefits:

- A European Childhood Cancer “Roadmap”(ESCP), IHE-based VTBs, Twinning Programs, Education

9 Bridging Roadmap & ESCP

- Healthcare cooperation and resolving expert fragmentation
- Identifying special therapeutic needs of young people with cancer requiring high expertise interventions with ECTG (special surgery, radiotherapy (proton therapy), stem cell transplants)
- Identifying European institution ready to engage as reference centres by establishing and/or rolling out virtual tumour boards for cross border advice
- Identifying European Institutions /hospitals offering top level expertise for special therapeutic interventions and referrals
- Visibility and Integration of PO National Parent and Survivor Organisations

SIOPE ERN Roadmap Guidance for Health Care Providers

Increased Transparency for Affected Families

10 “Roadmap” Actors

- **SIOPE Clinical Trial Group Network – Hubs of Coordination (HoC)**
 - as identified by the respective PaedCan-ERN – ECTG networks (Retinoblastoma, Hepatoblastoma, Wilms tumour, VRT,)
 - enriched by European Clinical Trial Group coordinating centres
- **European National Paediatric Haematology – Oncology Societies (NAPHOS) –HoCs**
 - identified by the respective representative /president of
European National Paediatric Haemato-Oncology Societies
- **Low Health Expenditure Rate (LHEAR) Country – HoCs**
 - Health Care Provider able to provide standard baseline care for patients and able to partner in
Twinning with ECTG–HoCs and receive virtual advice in int. tumour boards
- **CCI-E / EPAG HoCs**
 - Parent and Survivor Organisations www.ccieurope.eu

11 Achievement: 22 ESCP launched!

- Acute Lymphoblastic Leukemia (ALL) in Children and Adolescents
- Acute Myeloid Leukemia (AML) in Children and Adolescents
- BTG Overview Document
- Medulloblastoma
- Childhood Intracranial Germ Cell Tumours
- Rare CNS embryonal and sarcomatous tumours and Astroblastoma, MN1-altered
- Ependymoma
- Craniopharyngioma
- Low Grade Glioma
- Advanced intraocular unilateral retinoblastoma: non-conservative management
- Adrenocortical tumours in children and adolescents
- Salivary Gland Carcinoma in Children and Adolescents
- Nasopharyngeal carcinoma in children and adolescents
- Pleuropulmonary Blastoma in Children and Adolescents

- NUT carcinoma
- Standard Clinical Practice Recommendations for Ewing Sarcoma
- Pediatric-Onset Langerhans Cell Histiocytosis
- European Standard Clinical Practice Recommendations for Non-Hodgkin Lymphoma of Childhood and Adolescence
- High-Risk Neuroblastoma
- Low-risk NBL
- Rhabdomyosarcoma
- Towards European Standard Clinical Practice (ESCP) guidance for individuals with familial leukemia

- 2021
- 2022
- 2023



12 ERN Developments

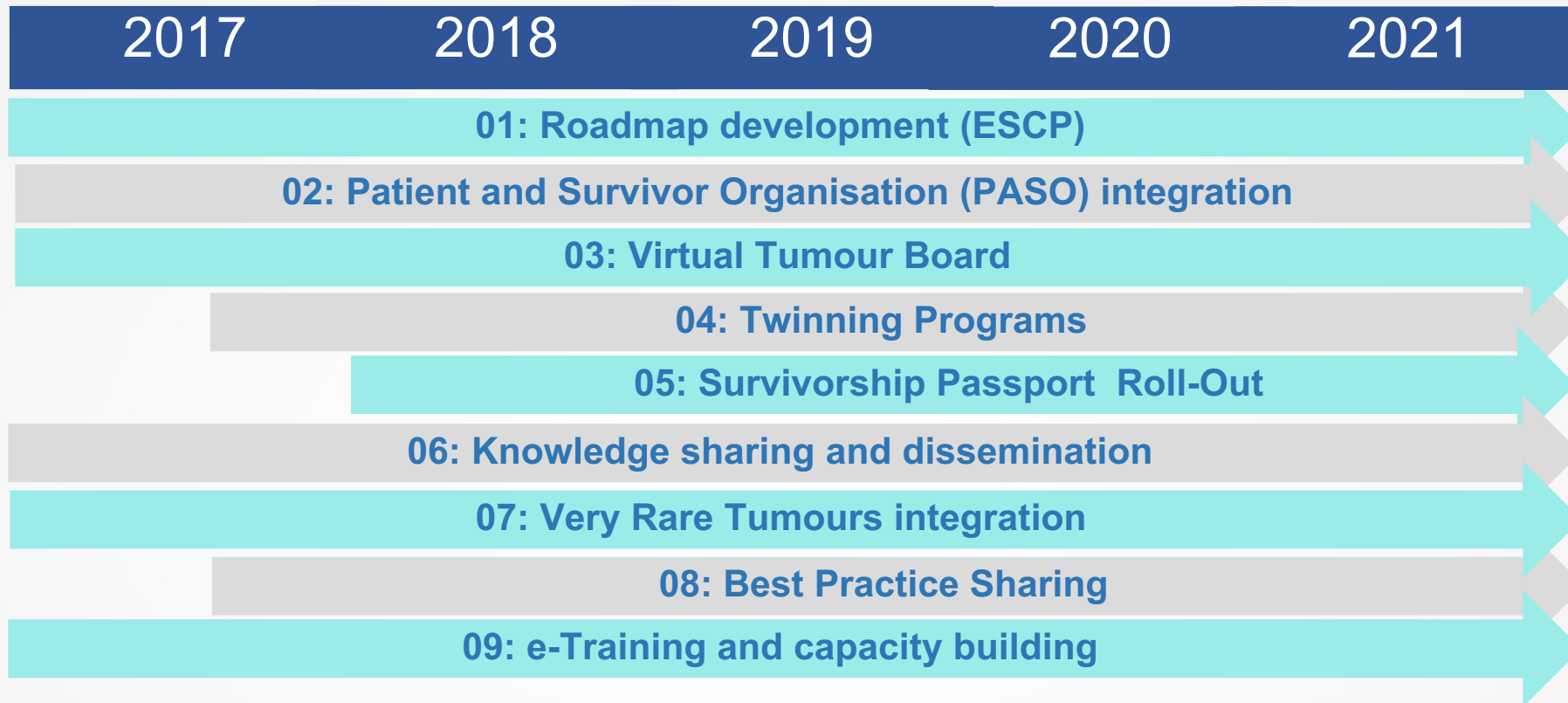
- Technically ready for release
- Last policy agreements need to be put in place before public release
- Specific modules available at release:
 - Acute Lymphoblastic Leukemia
 - CNS Germ Cell Tumour
 - High Risk Neuroblastoma
 - Langerhans Cell Histiocytosis
 - Medulloblastoma
 - Non-Hodgkin Lymphoma
 - Retinoblastoma

13 ESCP Webinars



- Initiated by Andishe Attarbaschi and Ruth Ladenstein as part of the ERN PaedCan Educational Program
- The ESCP webinars accompany the ESCP documents
- They provide a summary of the information contained within them

14 ERN PaedCan's Objectives

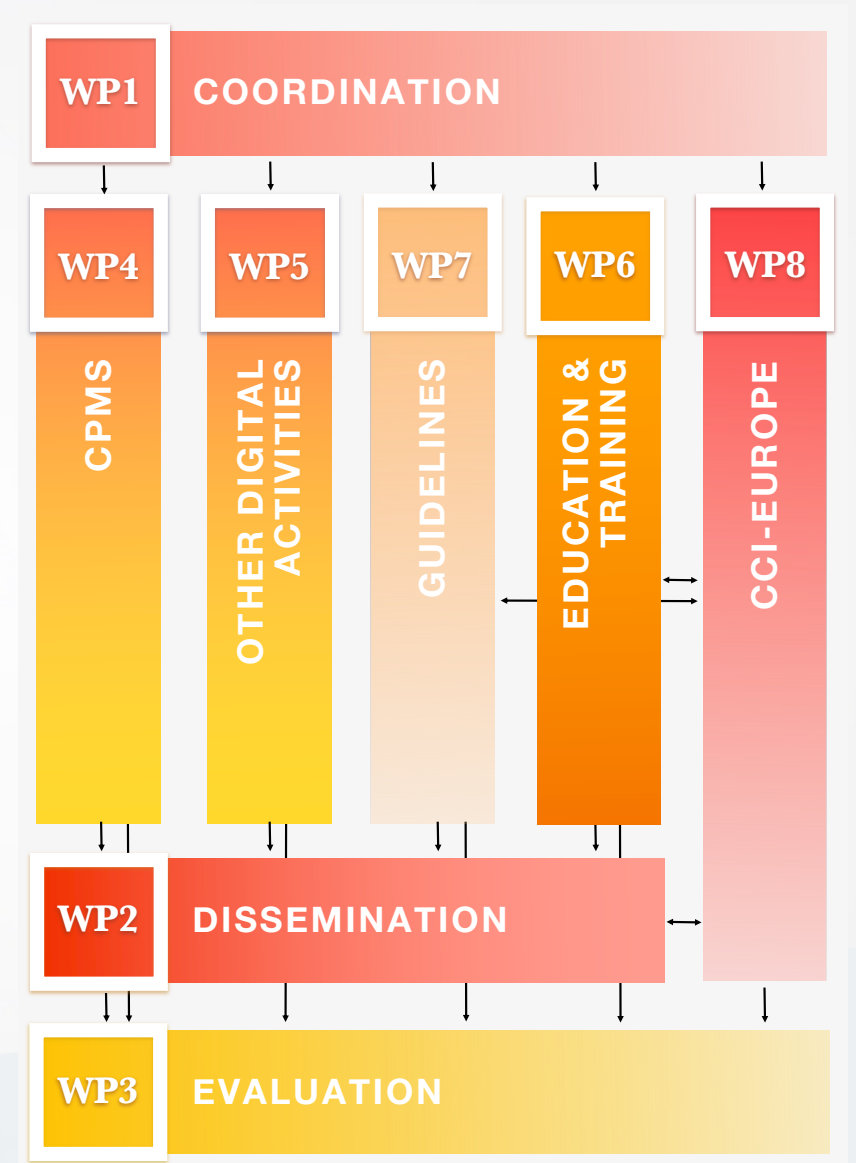


Twinning in Research and Education to improve survival in Childhood Solid Tumours in Lithuania

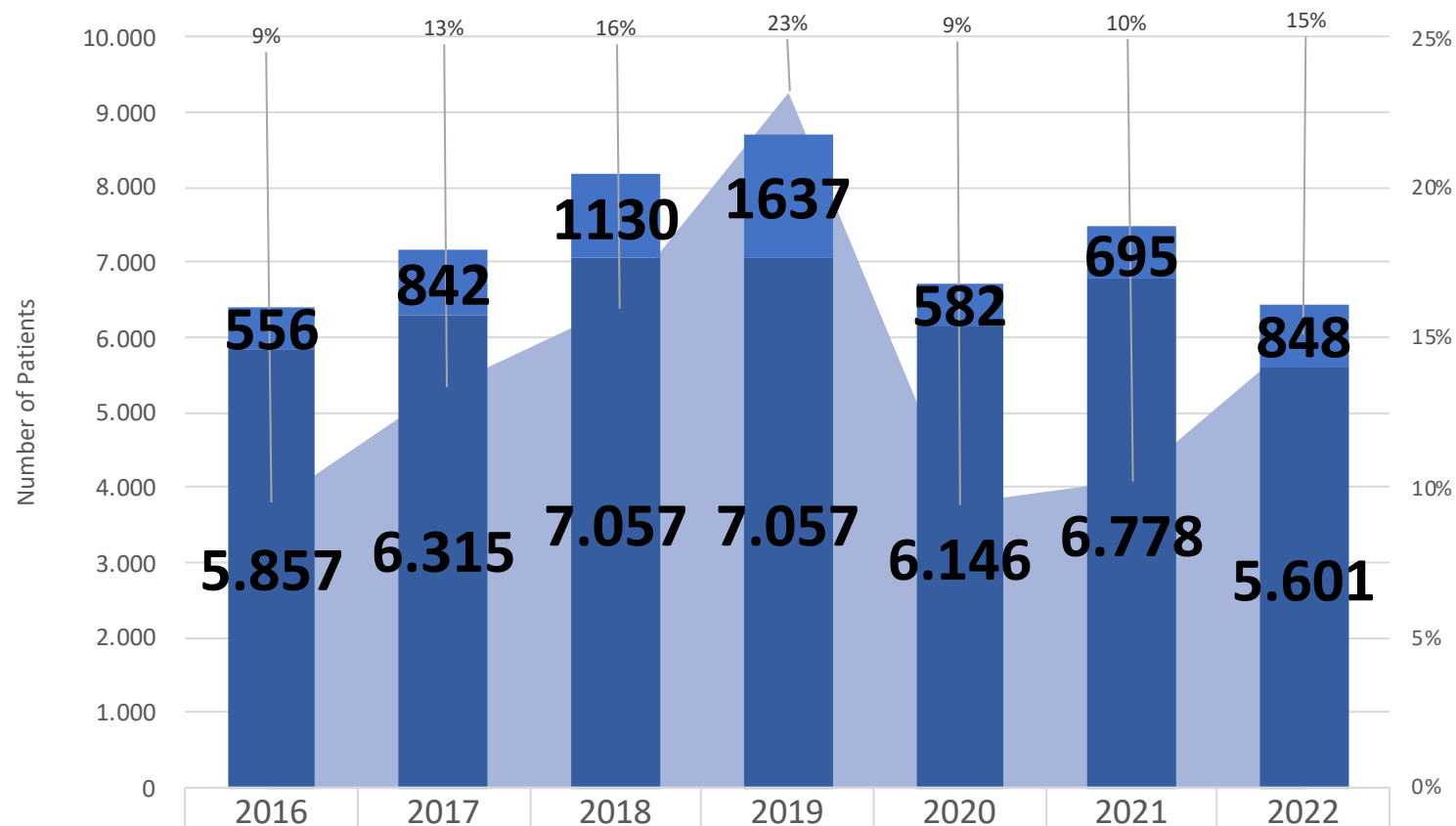


15 Bridging Grant

- Period: 01.03.2022 – 31.08.2023 (18 months)
- Mono-beneficiary grant
- Budget: 1M EUR, 100% funding (700k EUR per year vs. 200k EUR and 80% funding) BUT the pre-financing only arrived at the end of September
- 8 Work Packages

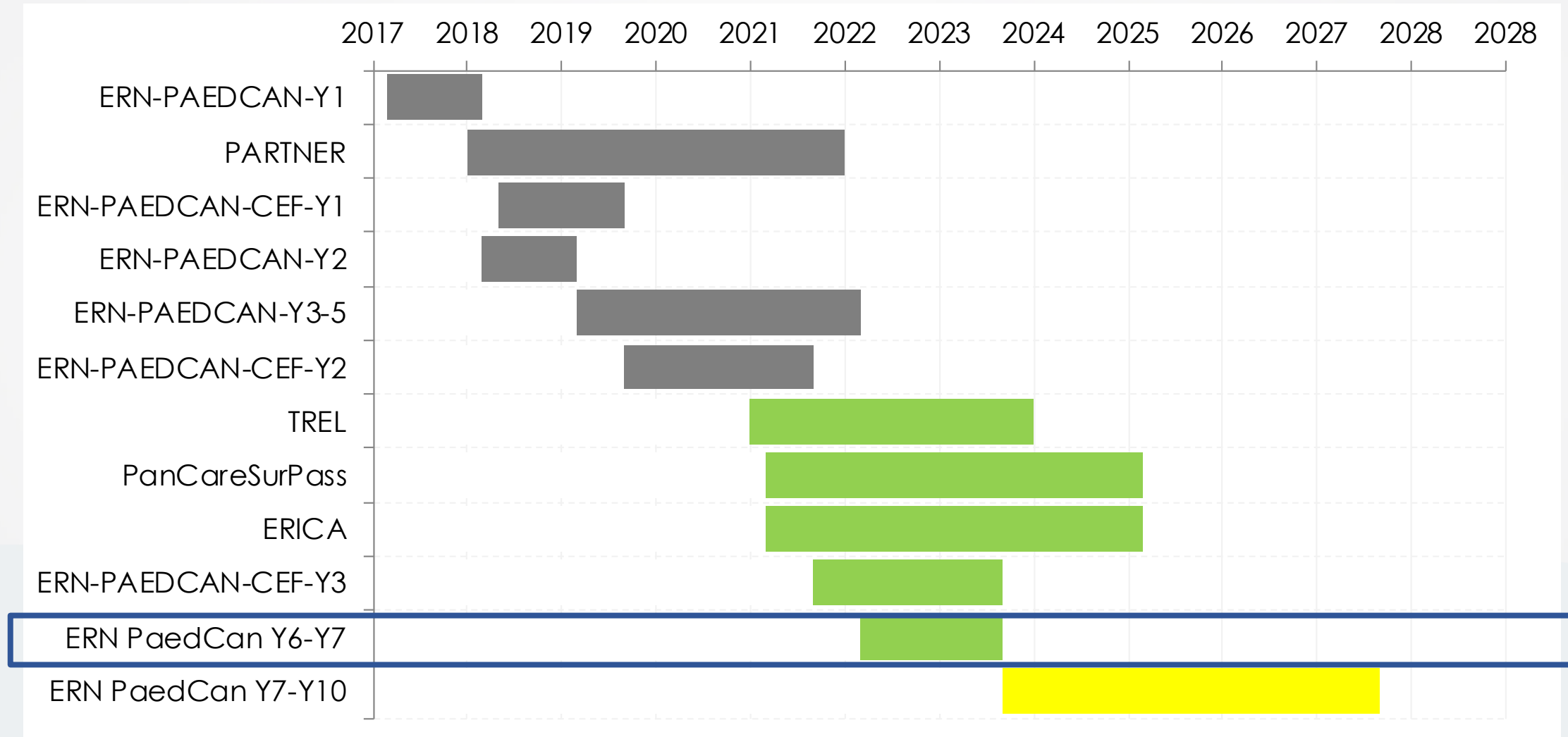


ERN PaedCan Number of patients and cross-border referrals, and its proportion by year



■ Proportion of CB referrals	9%	13%	16%	23%	9%	10%	15%
■ Cross-border referrals per year:	556	842	1130	1637	582	695	848
■ Total number of patients per year	5.857	6.315	7.057	7.057	6.146	6.778	5.601

17 Interplay of EC Projects with ERN PaedCan



18 ERN PaedCan Management Team



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ERN PaedCan
Coordinator



Zoltan Dobai
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1 Introduction to CPMS

- Clinical Patient Management System
- It is a dedicated IT platform to connect ERN members for consultation requests
- Includes a variety of telemedicine tools, such as DICOM viewer
- Developed by Irish IT company OpenApp in 2017
- Provided for free to ERNs by DG SANTE
- Fully GDPR compliant

2 Clinical Patient Management System

- Clinical Patient Management System is the only official ERN patient management tool critical for:
 - Patient care, diagnosis and treatment
 - Virtual meetings to discuss and prepare outcome
 - Future clinical research
 - Collaborative online tools
- The focus is first on diagnosis and treatment for patients by providing tools for collaboration and virtual consultations



3 CPMS Users

- Health professionals defined by Article 3(f) of Directive 2011/24/EU
 - ERN Members
 - Guest users from the EU and EEA countries*
- Beneficiaries:
 - Patients
 - ERN healthcare professionals
 - Other healthcare professionals
 - Researchers



*EEA=European Economic Area (EU + Norway + Liechtenstein + Iceland)

4 CPMS Pathway

- CPMS is a tool designed for and dedicated to consultations between doctors

→ Patients cannot access the system

- Pathway:

- Find ERN PaedCan Member in your country

<https://paedcan.ern-net.eu/home/member-institutions/>

- Establish contact between attending physician and PaedCan representative

- Attending physician or PaedCan representative will bring case to CPMS

<https://paedcan.ern-net.eu/e-health/>

5 CPMS Expert Groups

- New function of CPMS, currently in Pilot Phase
- Panel discussions for certain disease entities can be directed to predefined Expert Groups
- They meet on a regular basis to discuss consultation requests coming in through ERN PaedCan
- Long term goal: have all ECTGs represented as Expert Group in CPMS

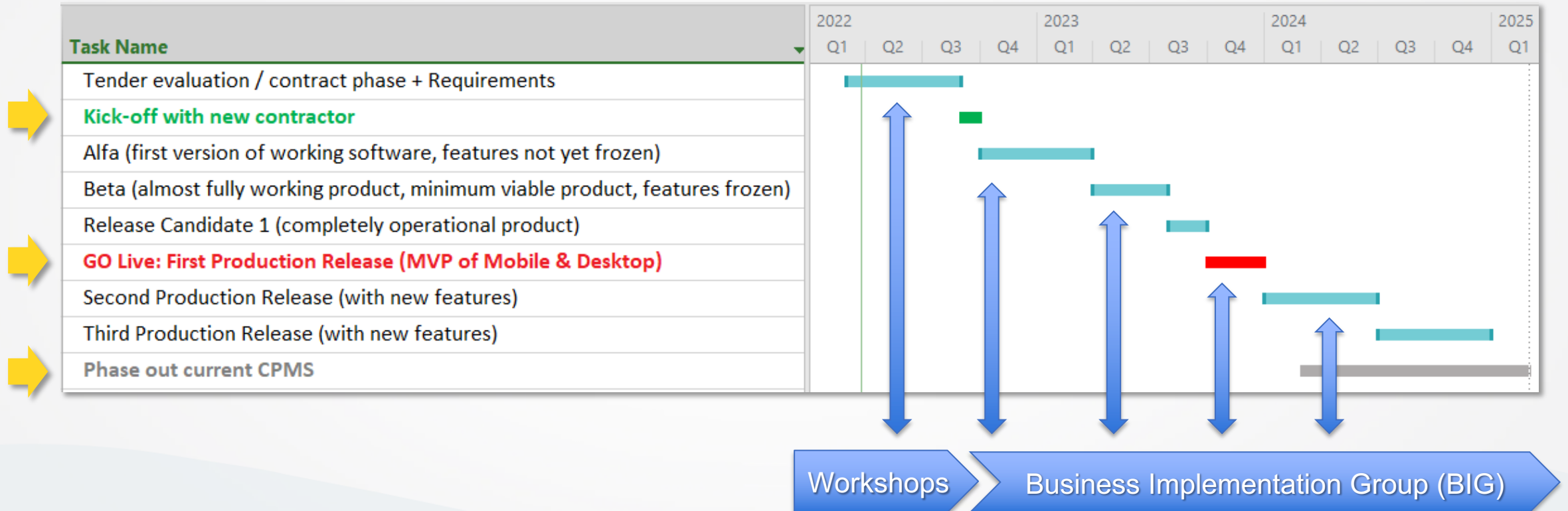
6 Expert Groups in Pilot Phase

- **Brain Tumours** (lead Stefan Rutkowski) UKE Hamburg
- **Ewing Sarcoma** (lead Uta Dirksen) UK Essen
- **Germ Cell Tumours** (lead Gabriele Calaminus) UK Bonn
- **Osteosarcoma** (lead Stefan Bielack/Stefanie Hecker-Nolting) Klinikum Stuttgart
- **Soft Tissue Sarcoma** (lead Monika Sparber-Sauer) Klinikum Stuttgart
- **Very Rare Tumours** EXPeRT Group (lead Dominik Schneider) Klinikum Dortmund

7 Challenges

- Operation of the CPMS as proposed in 2017 was always hindered by the lack of financial support
- Long established structures in paediatric oncology could not be translated to this new IT tool
- A rigid and difficult platform made it undesirable for medical professionals to use

8 Outlook: The New CPMS



9 outlook

- With the development of the new CPMS, a completely revamped telemedicine platform is in development
- It will serve the original idea and purpose in a vastly improved fashion
- It will remain to be used free of charge for ERN members and guest users



Thank you for your time !

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European Reference Networks (ERN) Paediatric Cancer

ANNE GOERES

03/04/2023



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CONTENT

1. Definition
2. Objectives
3. E PAGs
4. CCI-E's role & responsibilities
5. Outcomes
6. Next steps & challenges

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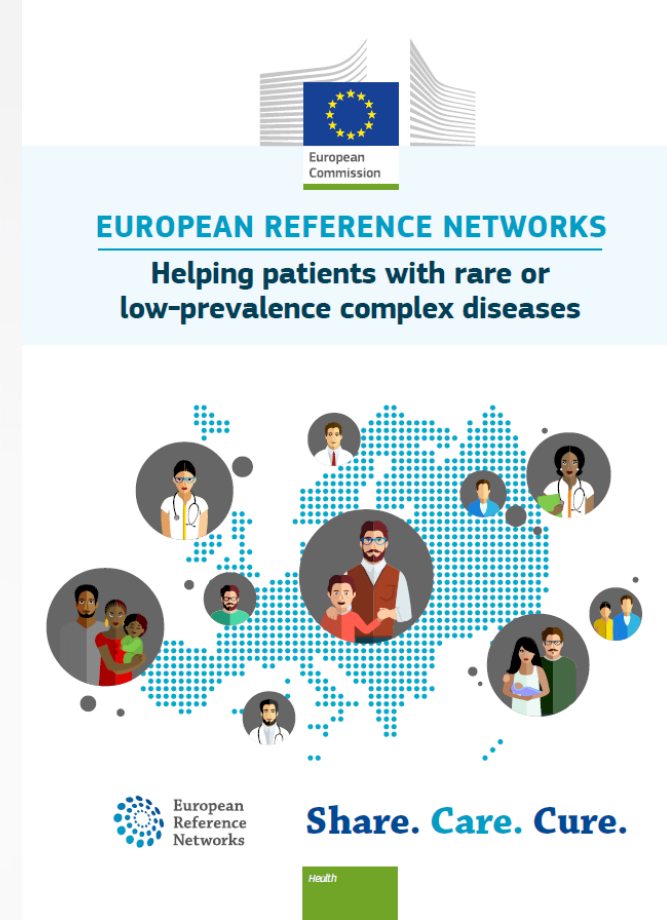
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DEFINITION



European Reference Networks' (ERNs) are a European Union's initiative that will make **national health systems cooperate in the interest of patients.**

The European Reference Network on Paediatric Cancer (ERN PaedCan) will **reduce inequalities in childhood cancer survival** by providing **high-quality, accessible and cost-effective cross-border healthcare** to children and adolescents with cancer, regardless to where they live.



1 OBJECTIVES

ERN PaedCan will

- **create a roadmap of healthcare centres** that are worldwide renowned for their expertise in treating paediatric malignancies. This network will facilitate the lives of both healthcare providers and of patients whose conditions require specialist expertise and tools not widely available due to low case volumes and a lack of resources.
- **implement eHealth technologies** and **improve interoperability** across different institutions (e.g. via a virtual paediatric oncology tumour board network to share expertise and advice).
- **help young patients and their families** make informed choices by providing clear information regarding access, quality, safety and reimbursement for treatments received in another EU country.






All this will represent more treatment options and less administrative obstacles for young patients and their families.

2

E PAG's

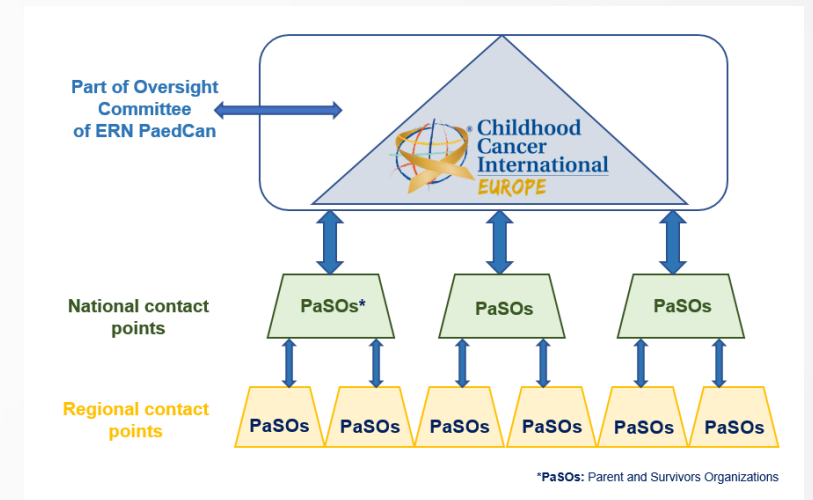
EURORDIS has developed a European Patient Advocacy Group (ePAG) for each ERN disease grouping. ePAGs will bring together elected patient representatives and affiliated organisations who will ensure that the patient voice is heard throughout the ERN development process.



<p>Anita Kienesberger Chair of CCI Europe Committee ePAG Steering Committee Member</p>		<p>Luisa Basset Vice-Chair of CCI Europe Committee ePAG Steering Committee Member Federación Española de Padres de NIÑOS CON CÁNCER</p>
<p>Anne Goeres CCI Europe Committee Member Fondatioun Kriibskrank Kanner</p>		<p>Carina Schneider CCI Europe Office Managing Director</p>
<p>Lejla Kamerić CCI Europe Committee Member Heart for kids with cancer – Bosnia and Herzegovina</p>		<p>Barbara Brunmair CCI Europe Office Projects Manager</p>
<p>Harun Šabić CCI Europe Committee Member Heart for kids with cancer – Bosnia and Herzegovina</p>		

2 CCI-E's role & responsibilities

- part of the ERN PaedCan's Oversight Committee
- provides the views of parents and survivors
- involved in the evaluation of the network at regular intervals to ensure transparency and
- contributes to the dissemination of patient information, policy, good practice, care pathways and guidelines in close cooperation with SIOPE.
- keep the community up to date and disseminate all important information about and innovations or reforms in the ERN.
- built a sub-network which links between the coordinator of the ERN PaedCan and the national contact points (Patients' and Parents' groups in Europe) .
- continue its advocacy activities also within the ERN and will try to represent the Patients' and Parents' voice as effectively as possible.
- contact point for affected children and their families and will incessantly work on being as supportable as possible.



3

OUTCOMES

- Up-dated list of CCI-E's national contact points (CCI-E NCP)
- Coordinated bi-monthly ERN PaedCan e-PAG meetings
- Recruitment of a coordinator (contract starting February 2023)
 - Unique contact point for all 63 CCI-E members in 34 countries
 - Contact and exchange with every single CCI-E NCP
 - Coordinate the educational efforts (Webinars) among our members
 - Contribution to the implementation of the ESCP's
- Exchanges and discussions about a potential benefits of the Paedcan ERN on European crises such as the Ukrainian war and patient evacuation



4

NEXT STEPS & CHALLENGES

- ESCP's implementation in coordination with the NAPHO's and CCI-E NCP
- Dissemination work with the NCPs to guide contact points all parents in Europe towards & through the ERN network
- Advocate for a better regulation for cross-border treatments (clinical trials)
- Coordination with other ePags (cancer)
- Joint comm strategy (SIOPE, CCI-E, ERN)
- Coordinate educational & training (Webinars) among our members
- Train and develop CCI-E's national contact points



Any questions?

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NEXT WEBINAR IS:

What is the European Standard of Clinical Practice (ESCP)?

On 15th May 2023

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