



Fostering Sustainability of Virtual Tumour Boards in the European Reference Network in Paediatric Cancer (ERN PaedCan)

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ICCD 2018 , 20 February 2018, 14:30 – 17:00

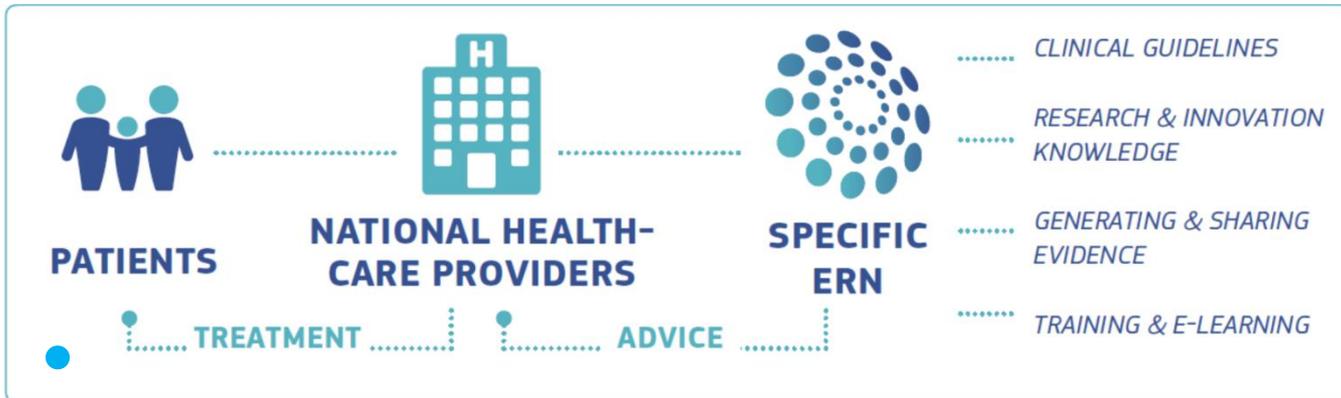
European Parliament (ASP 3H1), Brussels, Belgium

Hosted by MEP Elena Gentile (IT, S&D)



ERN PaedCan: Vision

- Equal and possible best paediatric cancer care and outcomes no matter where in Europe children live
- EC Vision on ERNs: A sustainable European Structure!





ERN-PaedCan: Key Benefits

- **A European Childhood Cancer Roadmap**
 - Guidance Document for Health Care Providers to direct affected families to approved Hubs of Coordination with special Childhood Cancer expertise (reference diagnostics , highly specialized interventions)

- **IHE based Virtual Tumour Boards (VTB) and Case Consultation Systems (VCS):**
 - Facilitate movement of information and knowledge rather than patients whenever possible.

- **Registries for Very Rare Tumour entities**
 - where case numbers are too low to consider a clinical trial setting .



ERN-PaedCan: Key Benefits

- **Twinning Programs and special Teaching & Training Programmes**
 - e-learning, movies, lectures, fellowship trainings etc.
- **Long term follow up including patient reported outcomes and advise for childhood cancer survivors**
 - Implementation of eHealth based supporting tools (Apps)
 - Survivorship Passport: condensed disease & treatment summary linked with late effect caution recommendations
- **Institution of a Virtual Late Effect Advisory Platform**



ERN PaedCan Members

2017

- 57 Full Members
- 18 Members States
- 28% members with gross national income <90% of EU average





3rd ERN Conference, Vilnius 2017

Inauguration of 24 European Reference Networks, March 9-10th



Vytenis Andriukaitis
EU Commissioner for Health and Food Safety

Xavier Prats Monné
Director-General, DG SANTE,
European Commission

Tapani Piha
DG SANTE, European Commission

Herman Brand
DG Santé, European Commission

Enrique Terol
DG Santé, European Commission

ERN PaedCan Kick-Off Meeting, Brussels June 29th



The Strength of Knowledge: 16 European SIOPE Clinical Trial Groups 3 Overarching Organisations

<https://www.siope.eu/european-research-and-standards/clinical-research-council/siopecrc/european-clinical-study-groups/>





Roadmap & Virtual Tumour Boards

- **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**

**SIOP ERN Roadmap Guidance for Health Care Providers
Increased Transparency for Affected Families**



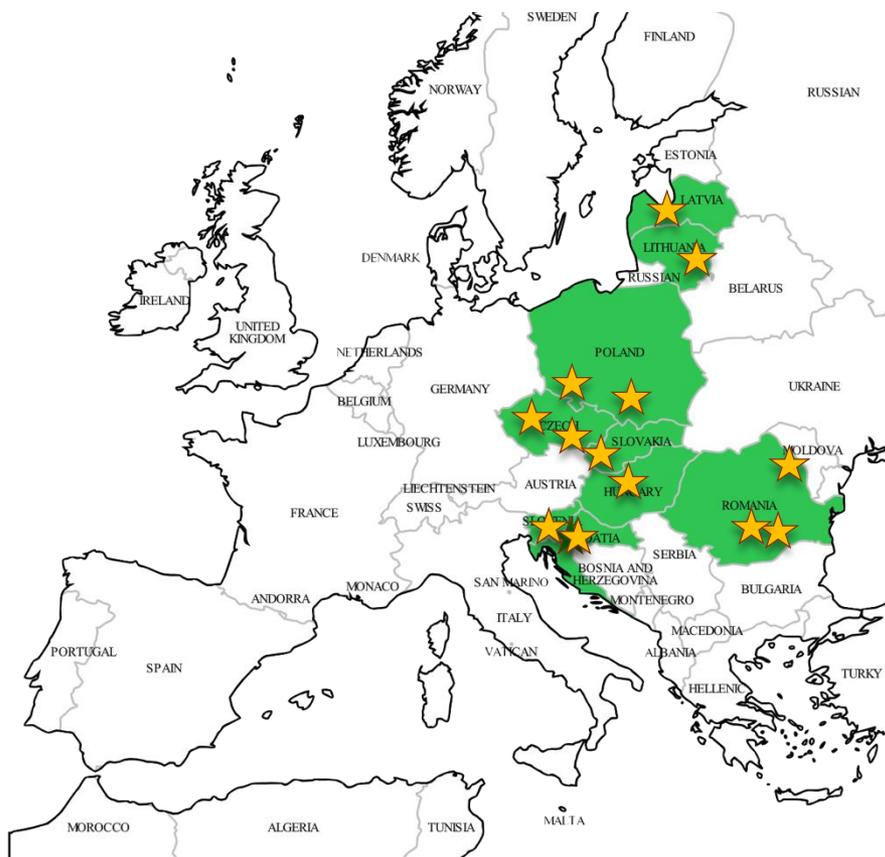
International Coordinating Sites of ECTG



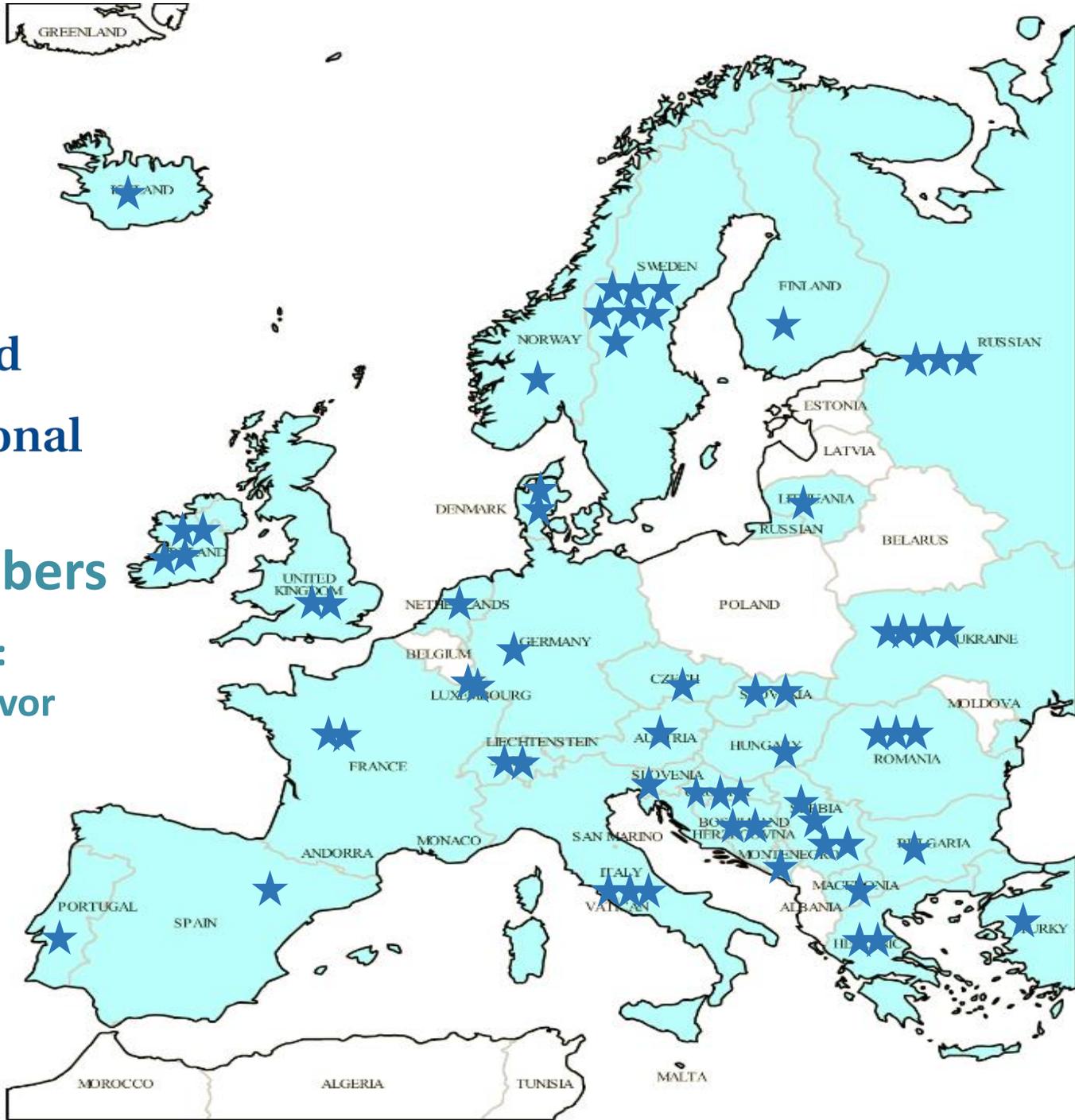
Country	Institute, Location
1 Austria	St. Anna Kinderspital (SAK)/Children's Cancer Research Institute (CCRI), Vienna
2 France	Institut Gustave Roussy (IGR), Villejuif
3 France	Institut Curie, Paris
4 Germany	Christian-Albrechts-Universitaet zu Kiel (CAU)
5 Germany	Charité Universitätsmedizin Berlin (Charité)
6 Germany	Universitätsklinikum Frankfurt
7 Germany	Olgahospital, Stuttgart
8 Germany	University Hospital Hamburg
9 Germany	University Children's Hospital, Bonn
10 Germany	Universitätsklinikum Münster
11 Italy	Azienda Ospedaliera di Padova (AOPD)
12 Italy	Universita degli Studi di Milano-Bicocca, Ospedale San Gerardo di Monza (Biondi, Jankovic)
13 Netherlands	Princes Maxima Centrum, Utrecht
14 Spain	Hospital universitario La Fé, Valencia
15 Sweden	Lunds universitet (ULUND), Lund
16 UK	University College London (UCL, Pritchard-Jones, Wheelan)
17 UK	Birmingham Children's Hospital (UOB)



LHEAR country HoCs: Targets of CBHC Cooperation



Country	Institute, Location
1 Croatia	Zagreb UHC
2 Croatia	Zagreb KDBZ
3 Czech Republic	Praha
4 Czech Republic	Brno
5 Hungary	Budapest SEMMELWEIS
6 Latvia	Riga
7 Lithuania	Vilnius
8 Poland	Wroclaw
9 Poland	Warsaw
10 Poland	Cracow
11 Romania	Bucharest ICF
12 Romania	Bucharest JOB
13 Romania	Jasi
14 Slovakia	Bratislava
15 Slovenia	Ljubljana




Childhood
Cancer
International

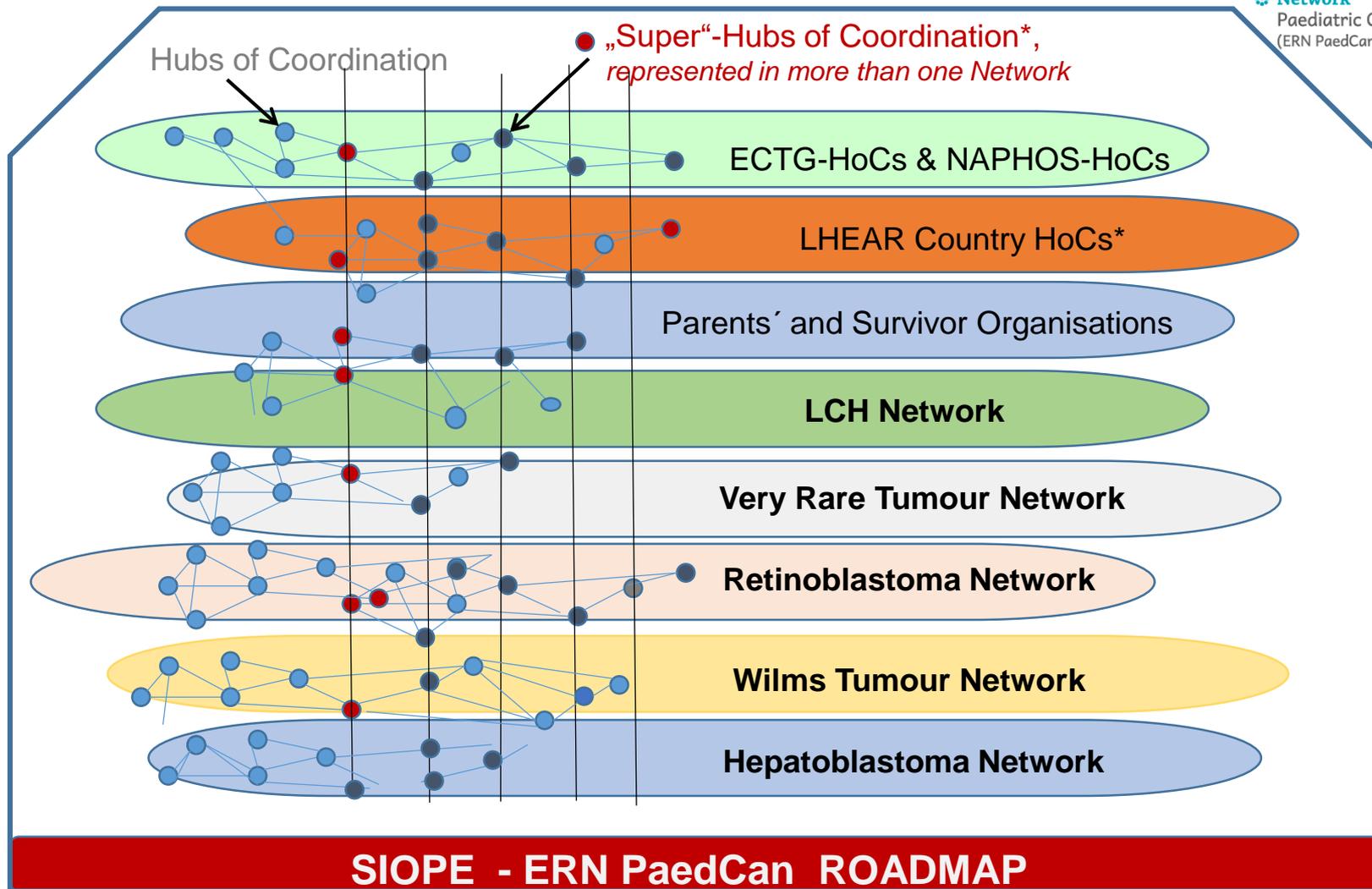
CCI Europe Members

As identified in 2017:

- 66 Parent & Survivor Organizations
- 33 Countries



Current Roadmap Layers





EC Clinical Patient Management System (CPMS):

**A safe way to run Virtual Tumour Boards in Europe !
A patient best care service beyond MS borders!
An eHealth Reality !**



CPMS Live: Pilot Phase Q4- 2017 /Q1 2018

A great tool, BUT...

Time spent on CBHC Advise still without compensation between MS !



Clinical Patient Management System (CPMS)

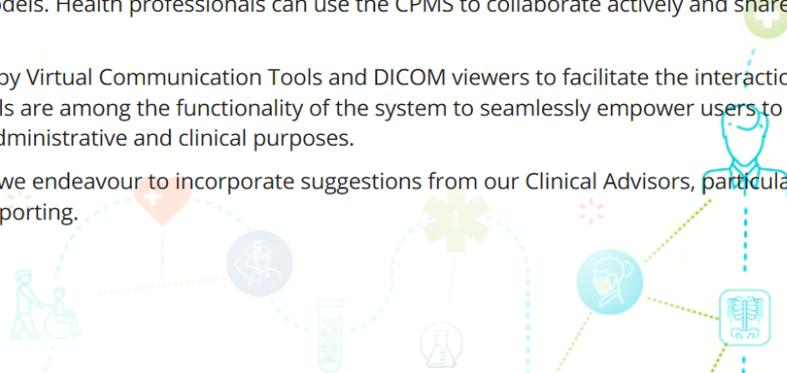
This site provides a demonstration of how OpenApp could use the Clinical Insight platform to deliver CPMS for European Reference Networks (ERNs).

The CPMS aims at supporting ERNs in improving the diagnosis and treatment of rare or low prevalence complex diseases across national borders of Member States in Europe.

The CPMS is a secure Software as a Service (SaaS) that enables health professionals to enroll patients using comprehensive data models. Health professionals can use the CPMS to collaborate actively and share patient within and across ERNs.

The CPMS is supported by Virtual Communication Tools and DICOM viewers to facilitate the interaction between clinicians. Reporting tools are among the functionality of the system to seamlessly empower users to generate reports of interest for administrative and clinical purposes.

The site may change as we endeavour to incorporate suggestions from our Clinical Advisors, particularly in the area of Graphics and Reporting.



You have logged out of the ERN server. You are still logged into the EU Login server. You have to close your browser to logout of the EU Login server

Secure Login

You can Login to the CPMS ERN through the EU Login Authentication Service.

[➔ Login via EU Login](#)

- Only authenticated users (EU Login) can access or request access to CPMS. To create an EU Login [click here](#).
- Only authorised users (SAAS) can access CPMS. To request authorisation to use CPMS [click here](#).
- To access or request access to the ERN Collaborative Platform (ECP) [click here](#).
- For more information about the European Reference Networks for Rare Disease, please visit ec.europa.eu.



USE CASE of a VTB Provider

St. Anna Children's Hospital & Children Cancer Research Institute

The ERN PaedCan Coordinator Site





CPMS – VTB Support Needs from local HCP

- Devoted working time of experts for ERN activities
- Agreement on manageable patients numbers
- Resources to “play” the system – Capacity of acting in the network
 - **Experts time in-house** (radiology, clinical experts, diagnostic experts)
 - **CHBC – VTB secretariat:** Administration of request/response
- Virtual advise creates a health care cost at local sites

Transparent and fair reimbursement system between Member States needed to make the common efforts sustainable !



Calculation Foreign Patient Board: Step 1 Screening of request

Calculation patient board/patient

Median cost to address a request to the patient board				
	corr. person employed	Duration /request per min	cost /min	Total costs
2 consultants min. A3/19	2	10	1.54	30.80
2 medical specialists min A3/13 (alternating request)	2	10	1.32	26.40
Administrative department	1	10	1.24	12.40
Secretariat	1	10	0.60	6.00
Secretariat response	1	10	0.60	6.00
		subtotal		81.60
		administrative charges	30%	24.48
		subtotal		106.08
		state aid ²	11.11%	11.79
		Summe		117.87

3 to 6 cases per patient board /week = 700€ - 1170€

Median 130 annual foreign patient requests (3 pts/week)

HCP - Step 1: 46 weeks median cost: 32.522€ - 53.820€



Step 2: Multidisciplinary St. Anna Tumour Board

Frequency weekly, 1 hour, median 6 patients well prepared

Calculation of average cost of tumour board / patient				
	corr. person employed	Time on Tumorboard / patient	Costs /min	Total Cost
5 Senior Experts: Consultant Paediatric Oncologist min A319	5	120	1.54	924.00
5 Medical Specialists A313 (alternating, "case owner")	5	120	1.32	792.00
Radiology preview	1	20	1.54	31.00
External Consultants [Surgeons (Orthopaedics, Paediatric, Organ experts)],	3	120		273.00
Administration	1	10	1.24	12.40
Equipment Library ²				75.00
Secretariat Preparation, invitation, reports etc.	1	25	0.60	15.00
		Subtotal		2,122.40
		Administrative charges ¹	30%	636.72
		Subtotal		2,759.12
		State aid ²	11.11%	306.54
		Total cost		3,065.66

1 CBHC tumour board patient /once a month* / once a week** = 3.066€* – 12.264€**

Median CBHC request /year (incl. 1-3 follow up's): 12 pts – to future 48 pts

Cost per Year : 12 months: 36.792€* / 46 weeks**: 141.036€**



Cost of Hospital Days 2017

EU-Tarif ¹	Non-EU Tarif ²	Days
1,166.00	1,383.00	1
2,332.00	2,766.00	2
3,498.00	4,149.00	3
4,664.00	5,532.00	4
5,830.00	6,915.00	5
6,996.00	8,298.00	6
8,162.00	9,681.00	7
9,328.00	11,064.00	8
10,494.00	12,447.00	9
11,660.00	13,830.00	10

Full diagnostic work-up:

5 – 8 days

- Interventions incl.
 Biopsy / Surgery / Pathology
- Blood chemistry ,
- Tumour markers ,
- Molecular profiling
- Respective Images
 (MRI, CT, PET, mIBG, US, ...)
- BM / LP
- need for anaesthesia to
 be considered

* Additional cost for families:

Travel (flight) : 2 parents / child 1. 500€

Hotel costs for 1 parent: 500€ (or more for family if day care)

Living costs during stay : 800€

2.800€



Potential cost per CBHC patient consultation

■ Step 1 : Screening Foreign Patient Board:	120€
■ Step 2: Foreign Patient St. Anna Tumour Board: (provision of full diagnostic work up by country of origin)	3.066€
<hr/>	
Total	3.7186€
± Ancillary CCRI diagnostics (molecular)	± 1.000€



Fact Summary

- Virtual advise provides quality assurance in health care and is cost effective for Health Systems
- May save 50% of incurred cost between MS !
- CBHC advise not integral part of local site / national budget provisions !

Virtual CBHC urgently needs new arrangements between MS



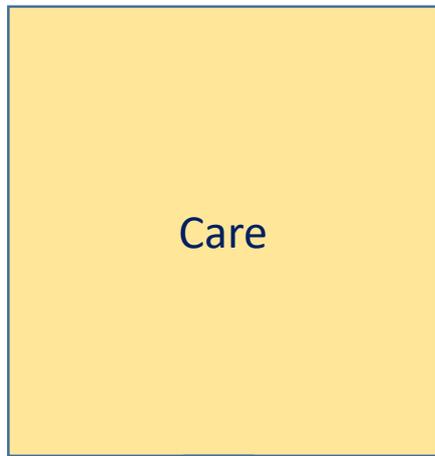
What is the S2 route?

- The S2 route entitles to treatment in another European Economic Area (EEA) country or Switzerland.
- Eligibility criteria
 - Written evidence of a full clinical assessment and a clinician's statement what treatment is needed and what the clinician considers to be a medically justifiable time period for treatment initiation.
 - The requested treatment is available in the proposed country's state healthcare scheme.
 - The same or equivalent treatment cannot be provided to the patient in the country of origin or cannot be delivered there within a time period that is medically justifiable.
 - The requested treatment is not experimental or part of a drug trial.
 - The requested treatment is not emergency treatment



Current MS Reimbursement for Best Care: S2

Per patient CBHC cost
 for a patient treated in another MS
 according to best standard care

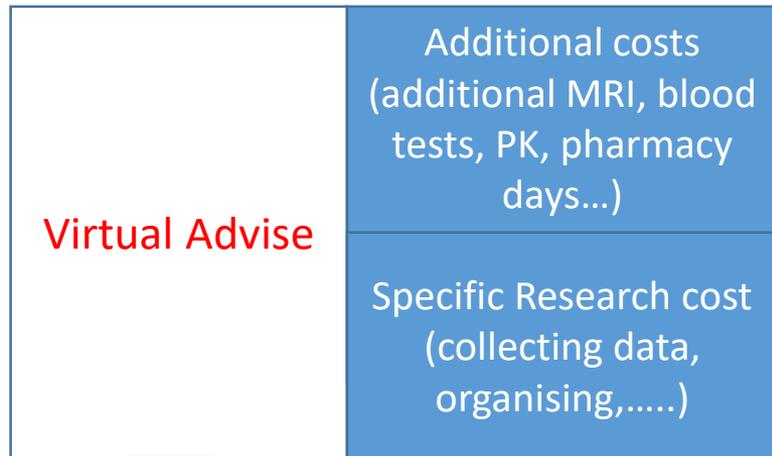


In the country → Health Insurance

Cross border → **S2**

Room for improvement

Not covered :
 Per patient cost for a patient
 Virtual Advise & Early trial access



Local Health Care System
 ?



"Clin. Research" Sponsor
 ?



Sustainability of Virtual Tumour Boards

- **Modify the S2 or create new S (X?) certificate**
 - To sustain virtual ERNs advise long-term
 - to allow cross border access to therapeutic innovations through participation in early clinical trials;
- **Explore solutions to facilitate travel and accommodation of patients and their family when referred to an innovation center.**



Towards a brighter future for our children with cancer

THANK YOU!





Conclusion

- Access to therapeutic innovations for children and adolescents with life-threatening malignancies
- Make information available
 - on expert sites for highly specialized care across disease entities (Road Map on ACCESS)
 - on early phase clinical trials across Europe publicly available, easily accessible, and understandable, with particular consideration for the needs of parents (i.e. link to parents organizations websites and different languages/level of technical details);
- Virtual Tumour Boards (VTB)
 - to discuss all patients with complex conditions in need for highly specialized therapeutic interventions in need for highly specialized intervention
 - To discuss disease at relapse, establish the best therapeutic strategy and define referral paths;

