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Towards a European Reference Network in Paediatric Cancer: The Network Coordinator View

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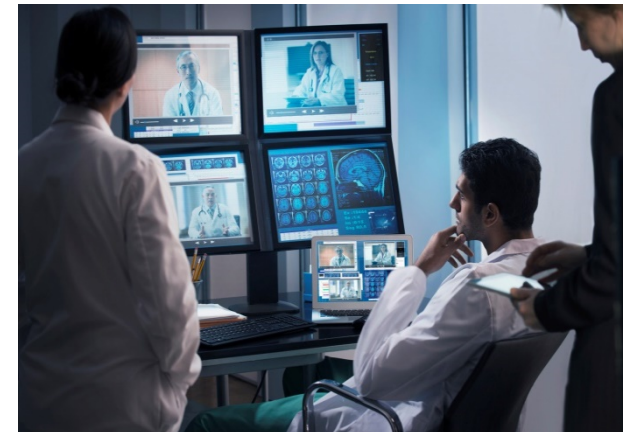


- ExPO-r-Net is a 3-year project to build a European Reference Network (ERN) for Paediatric Oncology.
- ExPO-r-Net aims to reduce the current inequalities in childhood cancer survival and healthcare capabilities in different EU Member States
 - ✦ Support cooperation on cross-border healthcare and mobility of patients, health-care professionals and information
 - ✦ Innovate healthcare delivery



The Paediatric Oncology European Reference Network

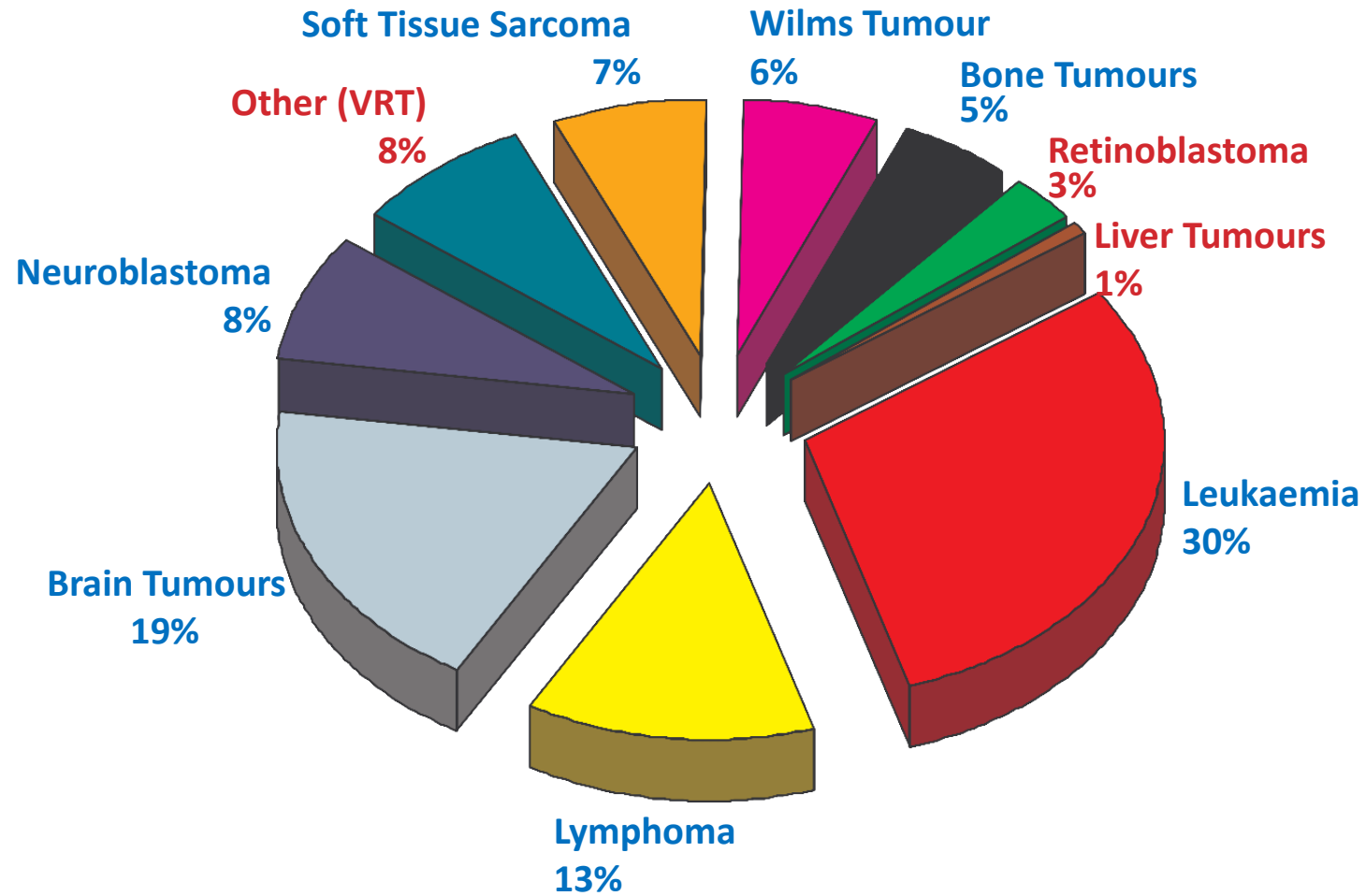
- will improve the standards of care across Europe
- will let children and young people with cancer benefit from high-quality, accessible and cost-effective healthcare
- <http://www.expornet.eu>



Childhood Cancer



- Rare Disease Definition: 1 in 2000 www.eurordis.org
- Childhood (< 15 years) Cancer Incidence in Europe: 1 in 6250
Kaatsch et al. Cancer Treat Rev. 2010, 36(4):277-85. Epidemiology of childhood cancer.



Paediatric Cancer is a public health challenge



- 6,000 children and young people die of cancer in Europe each year
- The quality and availability of paediatric cancer care widely varies across Europe
- 10% to 20% of them die from curable forms of cancer where quality care is not easily accessible.
- The outcome gap is even larger for paediatric cancers with poor outcomes



ExPO-r-Net PO-ERN



- ❑ **Will enhance ‘Cross-border healthcare’**
 - **Linking pre-existing reference centres with tumour boards to provide cross border advice.**
 - **Identification of the target groups** : children with special diagnostic and therapeutic needs requiring a particular concentration of resources or expertise.
 - **Improving access to high-quality health care** for children with cancer whose conditions require specialised resources or expertise not widely available due to low case volumes and lack of local resource.
 - **Provision of healthcare** to children and young people with cancer in a Member State other than the Member State of affiliation.



Stakeholders



- ❑ More than 60 Partners (Health care professionals, Hospitals, Institutes) from 17 countries
 - 18 core partners from 9 EU countries
 - > 50 Collaborating professional partners

Collaborating partners	
Number	51
Eastern European	20%
Western European	80%

- ❑ Involving parents and patients
- ❑ 8 Work Packages



Paediatric Oncology in Europe Background



□ Quality of the partnership

● European Society for Paediatric Oncology



● Integration

- European Clinical Research Council (**SIOPE - CRC**) for paediatric oncology (**NAPHOS / ECTG**)
- Childhood Cancer International (**CCI**) - Integration of parents and patients groups
- Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer: **PanCare**.

● Long standing successful relationships

- In EC funded projects
www.encca.eu, www.pancaresurfup.eu



- In European Clinical Trial Group (ECTG) environments,
- International meetings & stakeholder policy events including European Parliament

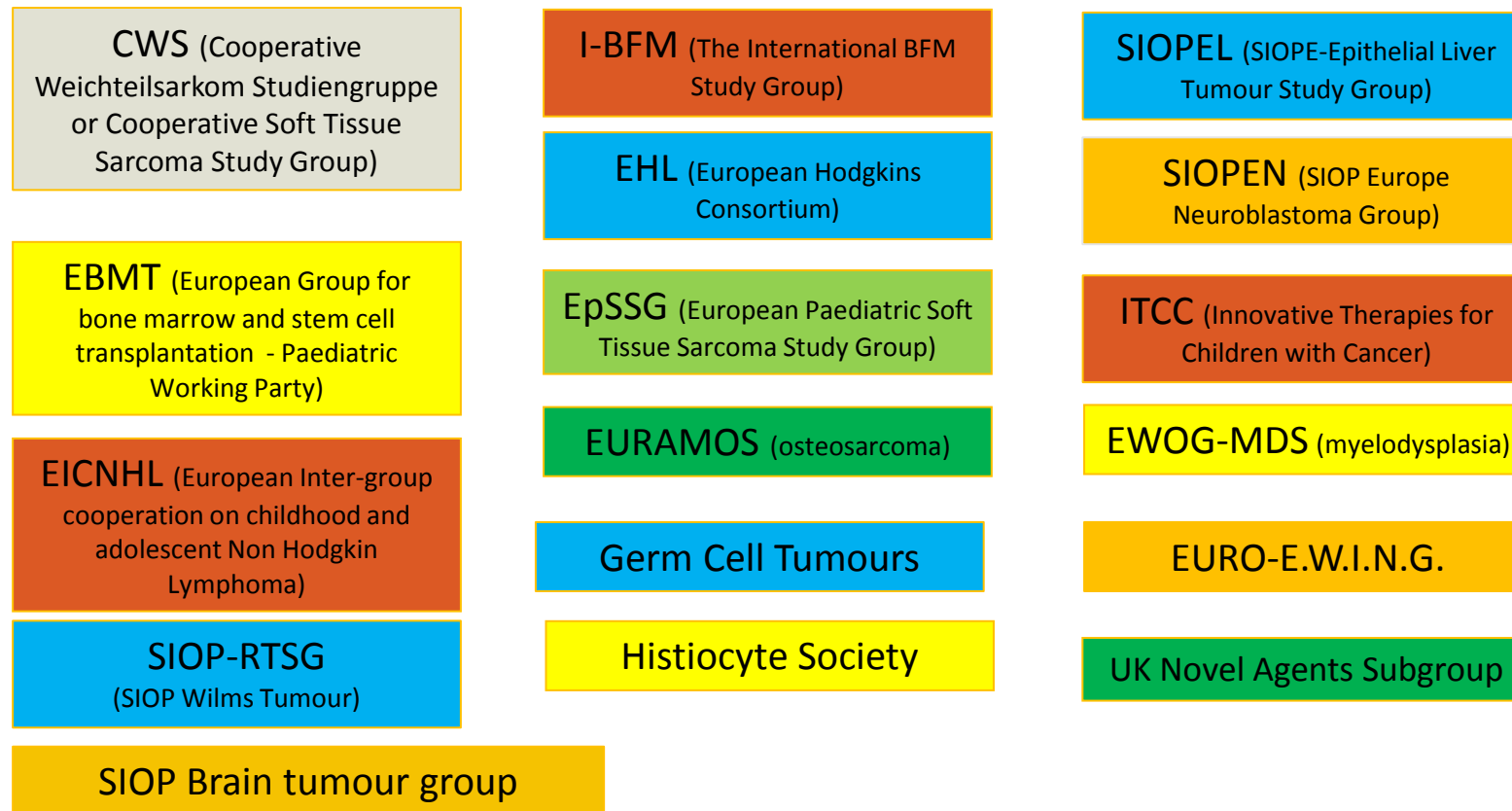




The PO-ERN Potential

CRC members: Chairs of European
Paediatric Oncology Clinical Trials Research Groups

>30 years of European collaboration within paediatric cancer entities



The PO-ERN Potential

CRC Members: Chairs of the National Societies
of Paediatric Haemato-Oncology in Europe

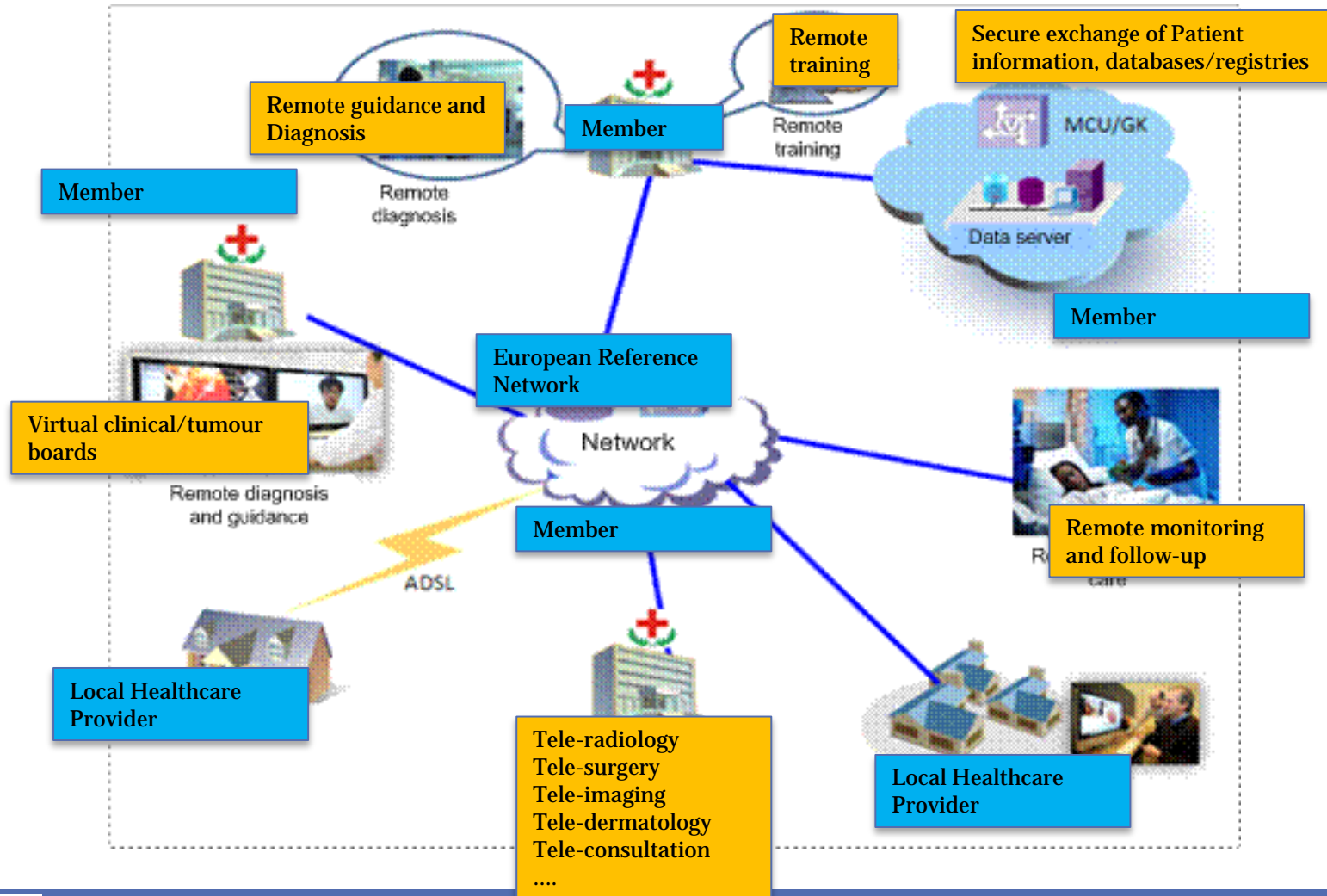


2015:
31 countries
1564 members

LEGEND SIOPE
Members of SIOPE (EU)
Members of SIOPE (non-EU)
Non-members of SIOPE, with NaPHOS (EU)
Non-members of SIOPE, without NaPHOS (EU)
Non-members of SIOPE, without NaPHOS (non-EU)



Telemedicine, IT solutions and tools are the basis for this project



ExPO-r-Net PO-ERN Roadmap

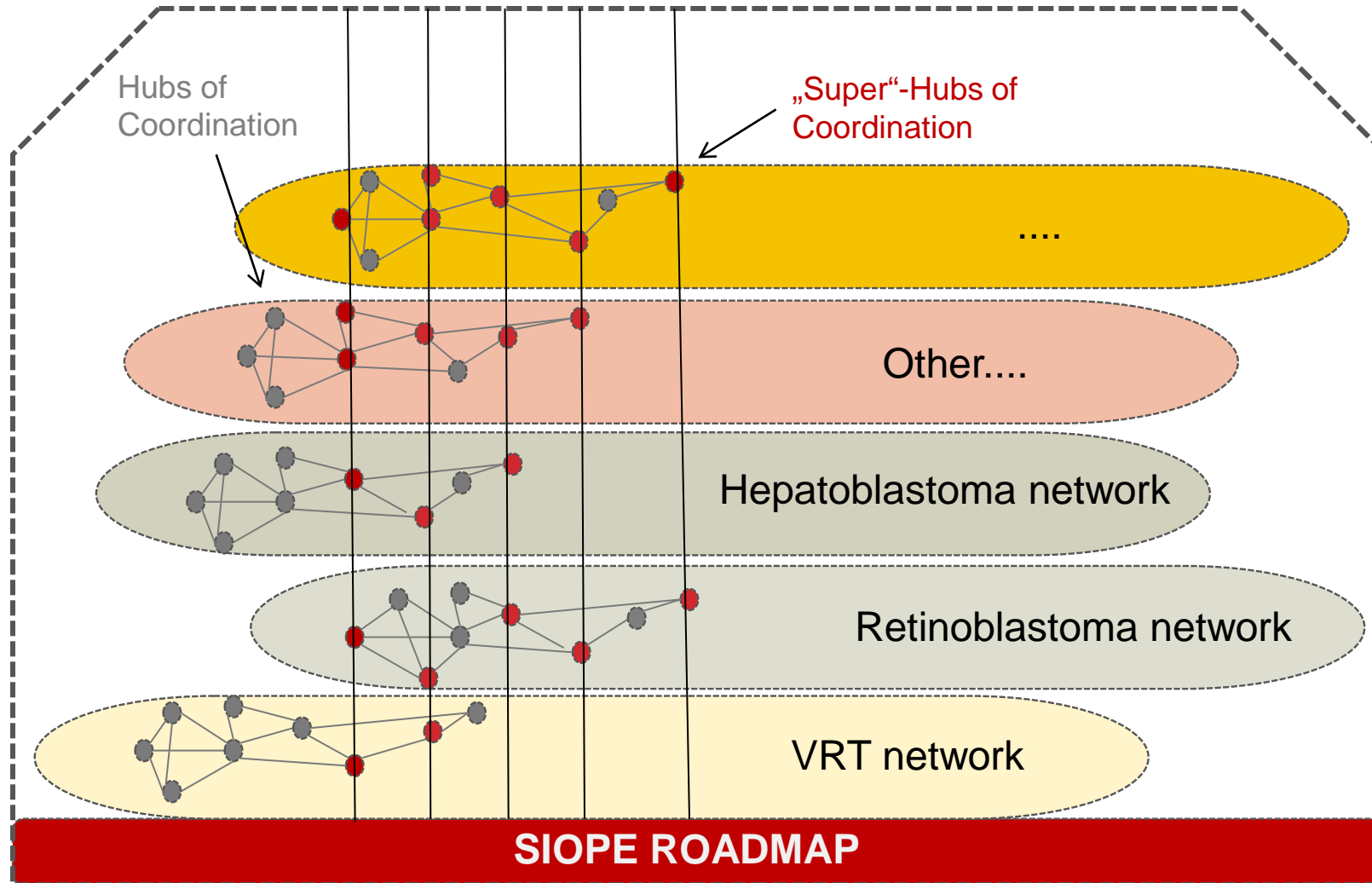


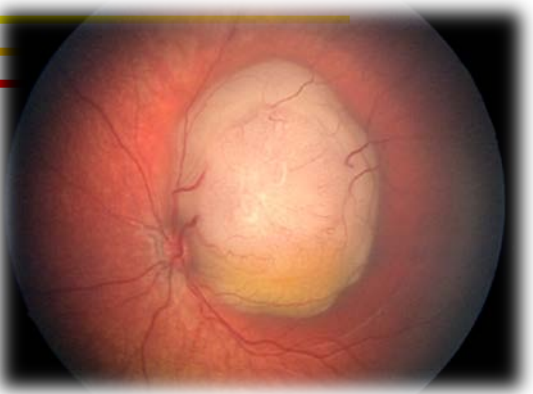
- ❑ **Addressing needs and challenges of cross-border healthcare co-operations and current expert fragmentation**
 - **Identifying special therapeutic needs** of young people with cancer requiring high expertise interventions
Examples: special surgery, radiotherapy (proton therapy), stem cell transplants
 - **Addressing the challenges:**
Examples: costs, resources, psychological burden and ethical aspects
 - Identify European institution ready to engage as reference centres by establishing a/o rolling out **virtual tumour boards for cross border advice**
 - Identify European Institutions /hospitals offering top level **expertise for special therapeutic interventions and referrals**



**Roadmap guidance for Health Care Providers
Increased transparency for affected Families**

ExPO-r-Net PO-ERN





Roadmap: Retinoblastoma



□ Background

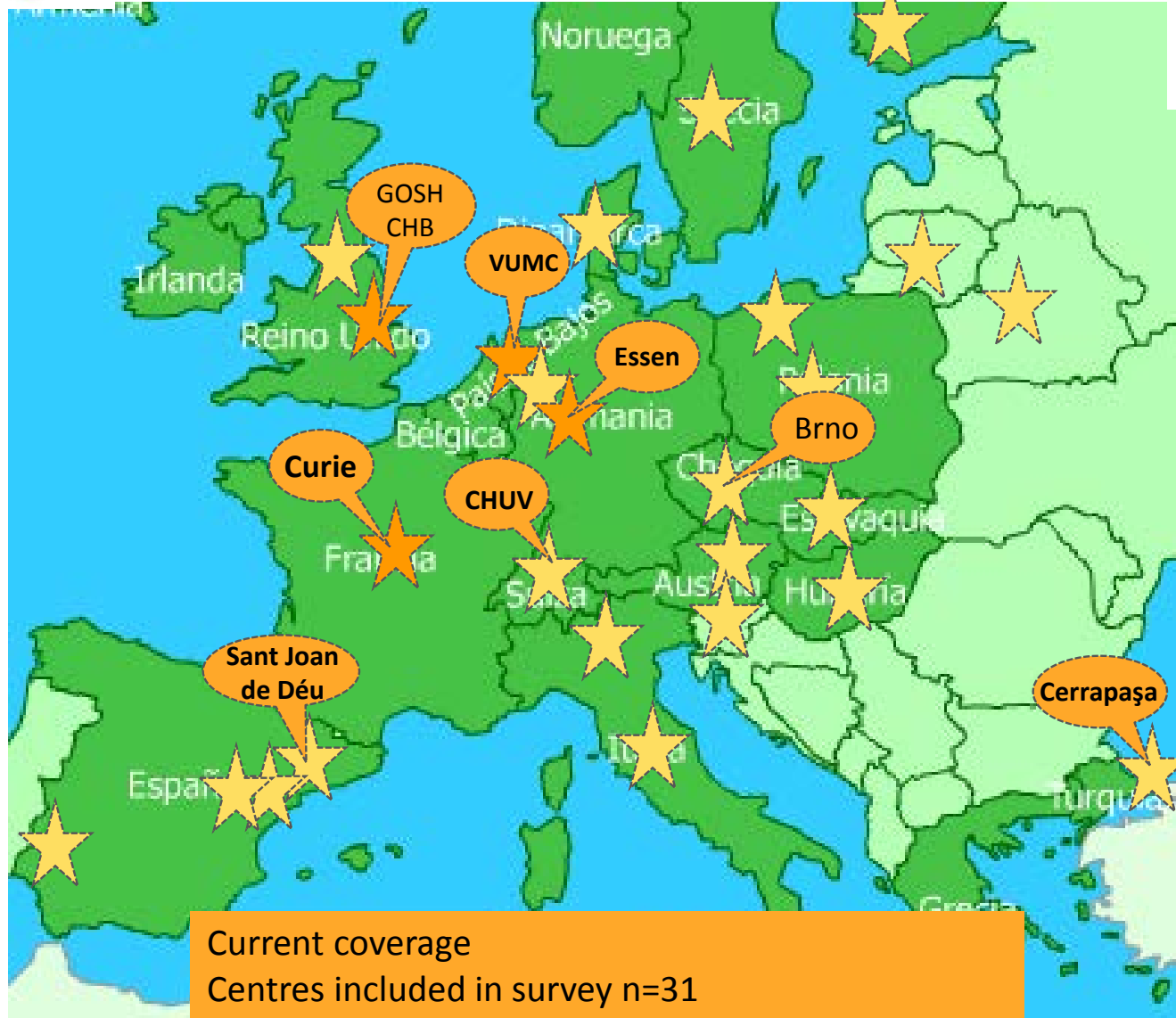
- A rare malignancy of young children with excellent survival.
- Implementation of vision-sparing treatments as major aim.
- **Major changes in treatment paradigms** : intra-arterial and intravitreal chemotherapy , use of pre-enucleation chemotherapy in high risk children
- Actual status: highly specialized multidisciplinary care in a few centres (global leaders), still fragmented in EU countries with low patient accrual.



EUROPEAN
RETINOBLASTOMA
GROUP



EURbG Hubs of Coordination (HoC)

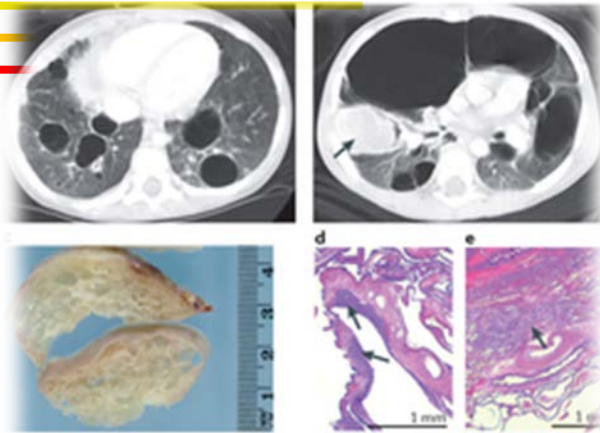


Current coverage
Centres included in survey n=31

EURbG

Varying Hubs of Expertise

HoC	#Pts	Intra-arterial	Brachytherapy	Research lab	Imaging	Extraocular
Paris	++++	+	+++	+++	+++	+++
Essen	++++	+	N/A	+++	++	+
Lausanne	++	+	+++	+	+	+
Siena	++	+++	+++	+	+++	+
Barcelona	+	++	++	+++	+	++
UK	++	++	++	+	+	+
Amsterdam	+	-	++	+	+++	+

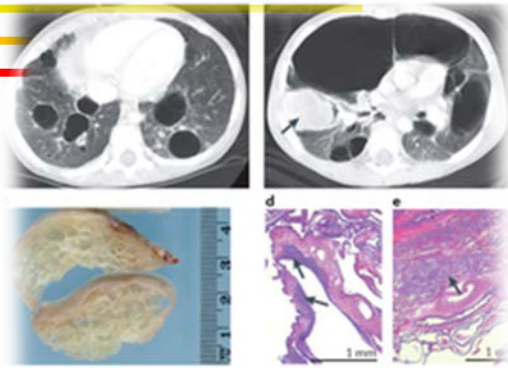


Roadmap: Very Rare Tumours



□ Background VRT

- VRT represent a range of very different entities. Each of them own peculiar diagnostic, clinical, biological and treatment features.
- VRT - even large paediatric oncology centres see very few cases each year
- **No standard treatment to recommend**
- Often special diagnostic and treatment skills needed not available in every centre, i.e. special surgery according to site or radiotherapy technique
- **VRT in need of expert supervision with “knowledge of the tumour “**
- **Need to build the evidence !**



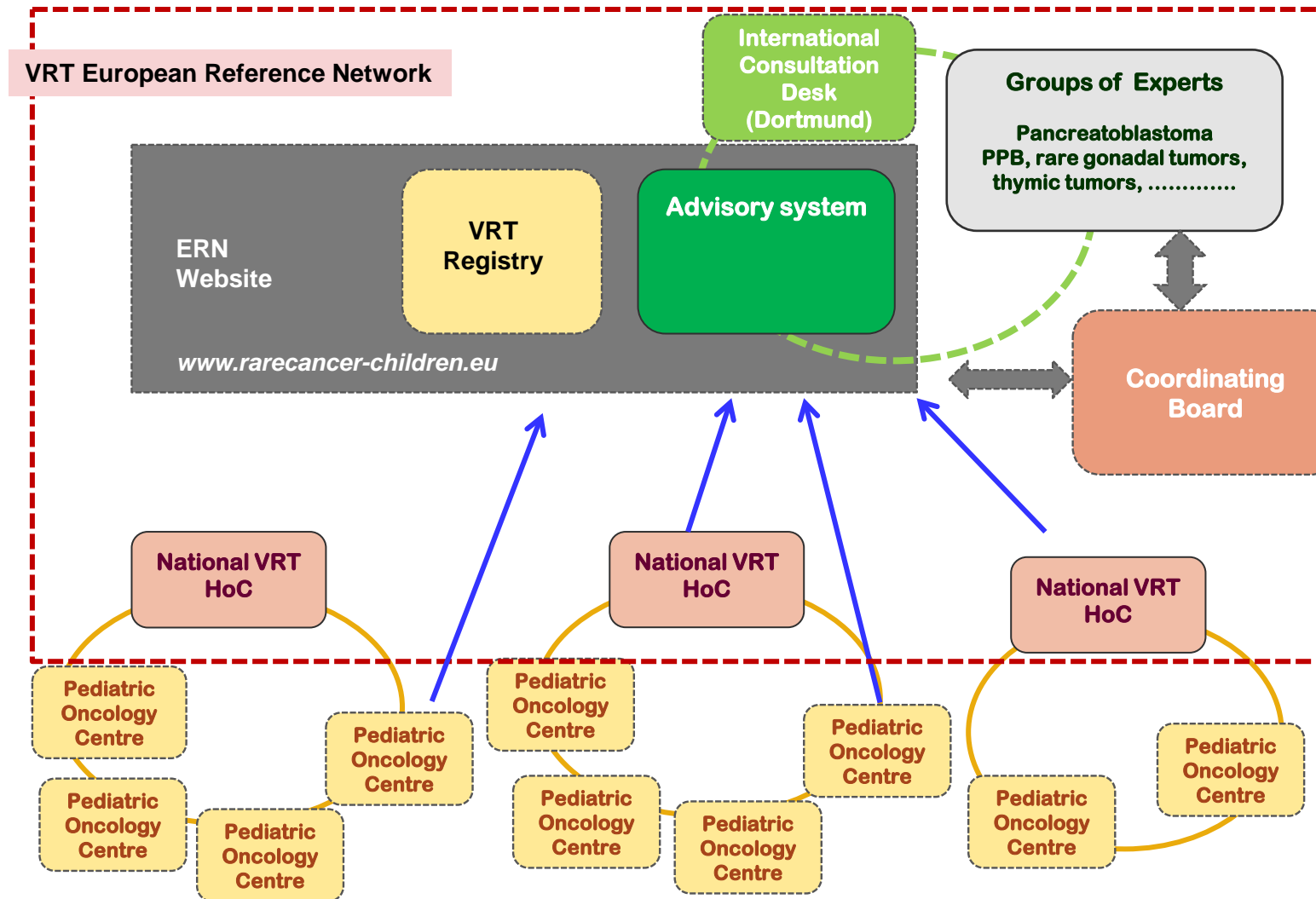
Roadmap: Very Rare Tumours



- **Integration of all VRT in a single framework.**
 - Not different networks dedicated to single VRT.
- **Advice on Diagnostics and Treatments for Children with VRT**
 - Necessary expertise cannot be located in a single centre.
- **Joint advice and supervision by a board of VRT experts in a VRT virtual tumour board**

VRT – ERN Structure

Need for complex governance structure!





A Cross Border Health Care NEED: PO Clinical Centres in European Countries with Low Health Expenditure Rates (LHEAR)

Childhood cancer survival in Europe 1999–2007: results of EURO CARE-5—a population-based study: Gemma Gatta, et al. Lancet Oncol 2014, Vol 15 (p37-45)

Self assessment questionnaire to LHEAR treatment centres to check European Standards of Care implementation

- Identification of centres in Central/Eastern Europe
- Future counterparts to ERN “hubs of coordination” (HoC) via virtual tumour boards.
- Pilot phase: evaluation in 5 potential HoCs and 2 LHEAR partners
(Sofia - Bulgaria, Bucharest - Romania)

Total Health Expenditure (per capita) US \$	Countries
> 2,000.-	Czech Republic, Slovakia, Slovenia
1,400.- to 1,800.-	Croatia, Estonia, Hungary, Lithuania, Poland
1,100.- to 1,200.-	Bulgaria, Latvia, Serbia
< 1,000.-	Belarus, Bosnia and Herzegovina, Republic of Macedonia, Romania, Ukraine



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IT STRATEGY FOR NETWORKS

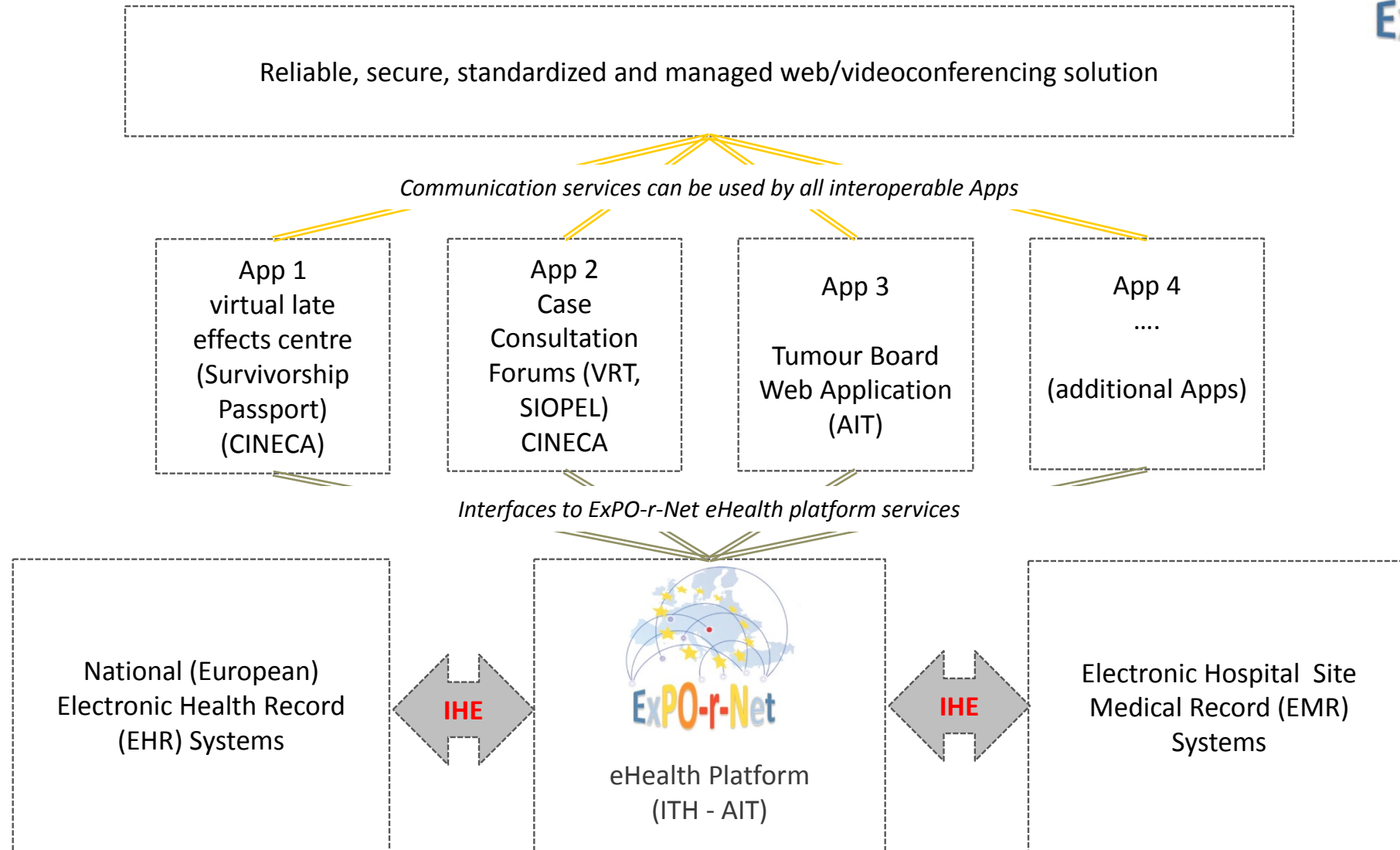
➤ VIRTUAL TUMOUR BOARDS

- Creation of an interoperability architecture for ExPO-r-Net
- ERN virtual tumour board based on E-Health
- **Move qualified information frequently**
but patients only electively for special health care interventions!



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eHealth Interoperability Architecture for ERNs

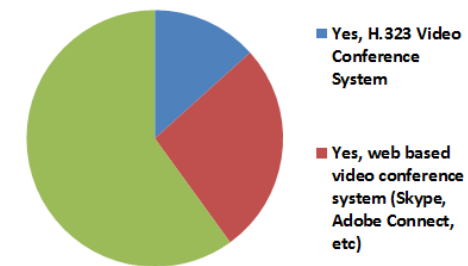


PO-Virtual Tumour Boards



- ❑ Evaluation of currently existing tumour boards through a 30-question survey
- ❑ Legal considerations
- ❑ Standard Operating Procedures (SOP)
- ❑ Results (SWOT Analysis, Example Spain)

<p>Strengths Paediatric Tumour Boards are currently integrated in the functioning of major Paediatric Oncology Units:</p> <ul style="list-style-type: none"> - In regular meetings. - With a designated coordinator. - With a defined core member group (Paediatric oncologist, radiologist, surgeon and pathologist). 	<p>Weaknesses Lack of: Paediatric Tumour Boards in small Paediatric Oncology Units.</p> <ul style="list-style-type: none"> - Standard operation procedures (SOPs) concerning case selection, preparation and recommendation follow-up. - Technical/administrative support and video-conferencing facilities. - Difficult case consultation "culture". - Participation in Virtual Tumour Boards.
<p>Opportunities:</p> <ul style="list-style-type: none"> - Cross-border health care Directive - ExPO-r-Net framework - IT developments (cloud systems) 	<p>Threats:</p> <ul style="list-style-type: none"> - Lack of interoperability among health ICT systems. - Case consultation compensation system. - Liability of advice consultation





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SURVIVORSHIP PASSPORT

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RIEPILOGO DEL TUMORE
Questo "Passaporto del Tumore" descrive la cartella clinica. Descrive e sostituisce la cartella clinica.

NAME SURNAME

Anagrafica
Data di nascita
Luogo di residenza
Contatto appartenente a
E-mail

Tumore maligno
Diagnosi
Data di diagnosi
Istituto
Categoria/Nome del tumore
Descrizione della sede
Alto rischio
Altre malattie
Predisposizione a sindromi
Altre condizioni mediche

Terapia
Primo trattamento
Il trattamento è stato eseguito altrove
Protocollo
Lista delle principali terapie

SURVIVORSHIP PASSPORT

SUMMARY OF CANCER TREATMENT
This Survivorship Passport is a short summary extracted from the information reported in the medical record. It describes the disease and its clinical course as well as the treatments you received. This document does not replace the medical record that is always available at our center.

NAME SURNAME Passport number: IT0100120130911578

Demographic data
Date of birth: 15/07/1993 Gender: F
Place of residence: GENOVA
Contact belonging to: Survivor
E-mail: maria.mcpherson@example.com

Malignant tumor
Diagnosis
Date of diagnosis: 07/02/2007
Institution: Istituto Giannina Gaslini, Genova - Italy
Cancer category/name: Hodgkin lymphoma
Site description: mediastinum
High risk: No

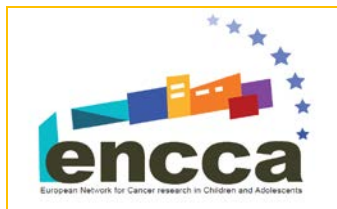
Other diseases
Predisposing genetic syndromes: No
Other medical conditions: Yes
nodular sclerosi

- Cross-border dimension of long-term follow-up:
Survivorship Passport with crucial treatment and follow-up data



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Structure



- Demographics
 - Diagnosis
 - Front line treatment
 - Chemotherapy
 - HSCT
 - Radiotherapy
 - Surgery
 - Relapse/Progression
 - Other relevant clinical events
 - Medical suggestions
 - Relapse after 1° end of therapy
 - Notes
- } 420 variables

ICD-O
(WHO or Cancer registries)

ATC

New coding (215 variables)

Before	2013	2014	2015
	January-June	July-December	January-June
			July-December
			January-July
Cardiomyopathy	Coronary / vascular disease		
SMN breast cancer	CV risk / Metabolic syndrome		
	Models of care / transition		
	Female gonadal toxicity		
	Male gonadal toxicity		
		Neurocognitive deficits, fatigue	
		Thyroid cancer/ dysfunction	
		Bone	
		CNS & other vasculopathy	
		GH deficiency	
		Hearing disabilities	
		Tubular/glomerular injury	
		Other secondary neoplasms	
		Miscellaneous Group 1	
		Miscellaneous Group 2	
IGHG	EBM method		
IHG & PCSF collabor	EBM method		
PCSF alone	"Pragmatic method focused on education"		
			Finishing final documents

14 IGHG+PCSF (2 completed + 3 ≈completed)
3 PCSF alone (transition + 2 miscellaneous)



Survivorship Passport



❑ Goals

- To build a virtual paediatric oncology expert reference network for late effects after treatment for cancer in childhood and adolescence
- To translate the Survivorship passport and relevant Guidelines into multiple European language

“...Survivor Passport is a cloud application available across countries/hospitals by any device in the internet through a secure protocol and user profile...”

❑ The possibility of a mobile app for the passport is under consideration

- Passport download and/or search for specific information
- Possibility of pop-up memos according to guidelines



Integrated Communication Strategy



Consistent identity

- Logo
- EU acknowledgement

Communication tools:

Promotional material

- ✓ Bookmark
- ✓ Flyer/Folder
- ✓ Roll-up Banner
- ✓ Pens and Post-its

Project bulletin:

- ✓ Quarterly Project eBlast
- ✓ Features in SIOPE Newsletter

Online resources:

- ✓ www.ExPOrNet.eu (incl. dissemination pack)
- ✓ Twitter #ExPOrNet



Broad External Dissemination



❑ Strategic liaison:

- ECCO – European CanCer Organisation (Member)
- SIOP – International Society of Paediatric Oncology (Continental Branch)
- Eurordis (Member)
- Rare Cancers Europe (Member)
- European Forum for Good Clinical Practice (Member)
- Health Data in Health Research Alliance (Member)
- Childhood Cancer International – CCI
- MEPs Against Cancer





Project Expected Impact

❑ The strategic relevance

- Incorporation of expertise across Europe to help patients getting access to the best possible information, treatment and care.

❑ The innovative contribution

- A clear roadmap
- Fostering eHealth solutions based on interoperability and standardisation



Because access to quality advise and care
saves children's lives



Because together, we are stronger!



The remaining major challenge for European Member States:

- **Cross boarder financial compensation system** for virtual cross boarder tumour board advise: invested FTEs in expert hubs!
- **Moving information is cheaper than moving families!**

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