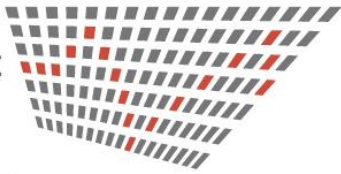


ehealth  
summit  
austria



himss Europe

In Kooperation mit



**24. – 25. MAI 2016**

Schloß Schönbrunn, Wien  
Apothekertrakt und Orangerie

PREDICTIVE MODELING IN  
HEALTHCARE –  
**FROM PREDICTION  
TO PREVENTION**

[www.ehealthsummit.at](http://www.ehealthsummit.at)

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**AIT**  
AUSTRIAN INSTITUTE  
OF TECHNOLOGY  
TOMORROW TODAY

 Österreichische Gesellschaft  
für Biomedizinische Technik  
Austrian Society for  
Biomedical Engineering

 OÖSTERREICHISCHE  
COMPUTER GESELLSCHAFT  
AUSTRIAN  
COMPUTER SOCIETY

**UNIT**

# “HEALTH MEETS RESEARCH”

## Concept of a long term follow up instrument for critically ill patients

Univ. Prof. Dr. Ruth Ladenstein  
St. Anna Children's Hospital &  
Children's Cancer Research Institute,  
Vienna /Austria

# eHealth for Research



□ „ .....eHealth is the cost-effective and secure use of information and communications technologies in support of health and health-related fields, including health-care services, health surveillance, health literature, and health education, knowledge and research“

*WHO, WHA58.28, eHealth, The Fifty-eighth World Health Assembly, 25. 05. 2005*



## Key issues addressed by the Directive

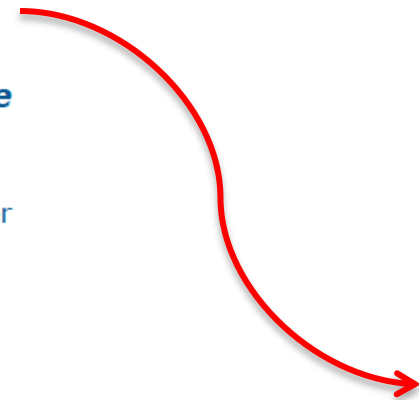


### *Directive 2011/24/EU of patients' rights in cross-border healthcare*



### *focussing on patients' rights & healthcare across the Union:*

- Right to **choose and be reimbursed**, under certain circumstances for, **healthcare provided** by public or private providers located in the EU.
- More **transparency about their rights**, treatment options or , the quality and safety levels of healthcare providers
- Strong focus on **cooperation among Member States**:



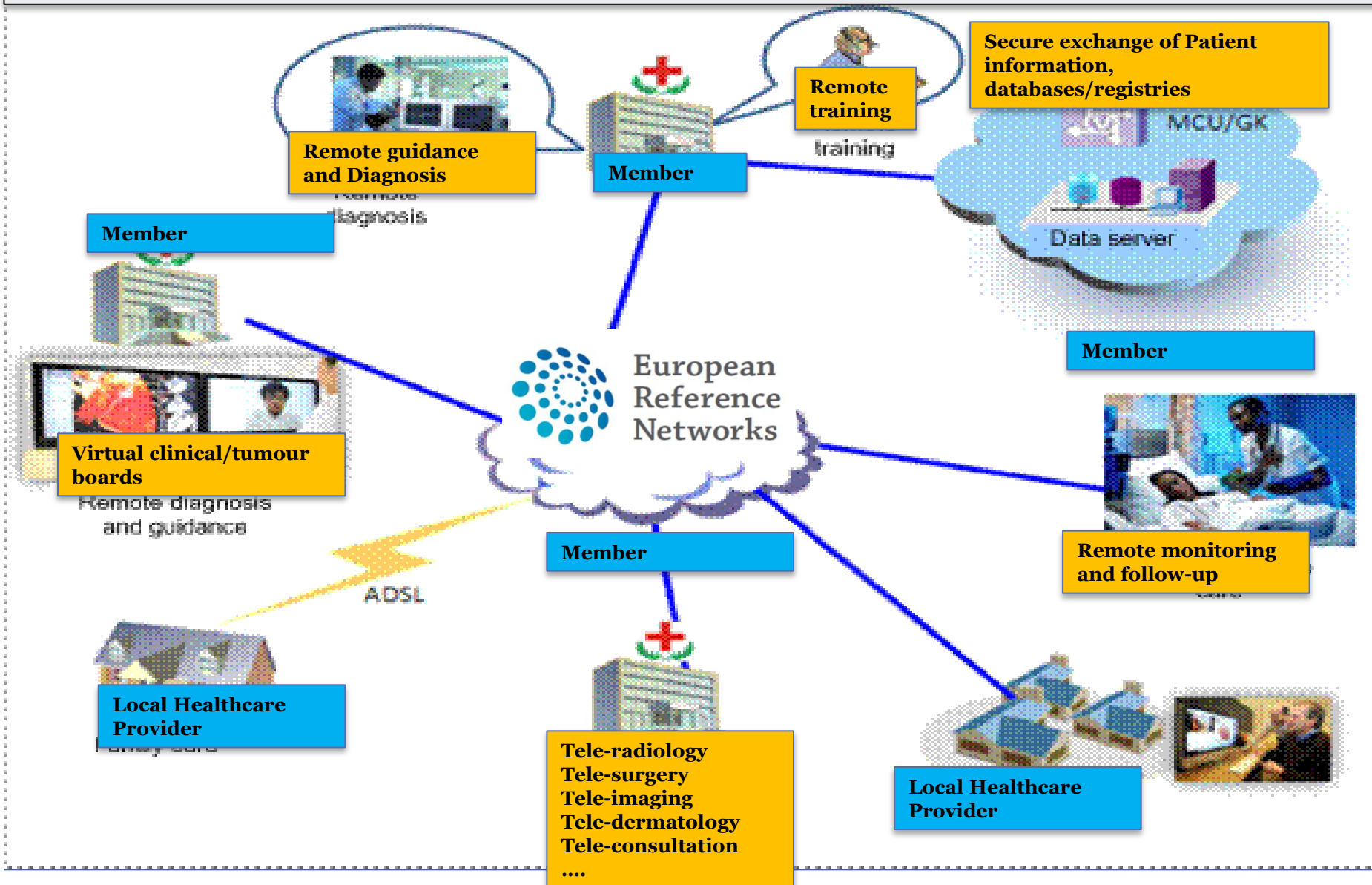
European  
Reference  
Networks

**Entry into force at National level 25 October 2013**

Health and  
Consumers

# THE EUROPEAN UNION VISION

## Telemedicine and other IT solutions and tools are the basis





# Paediatric Cancer is a public health challenge



- > 12.000 children and young people diagnosed in Europe each year
- 60 different types of cancer , > if biological markers considered
- 6000 die 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
- In 2020 - 500.000 survivors : 2/3 late effects





European  
Reference  
Networks



Co-funded by  
the Health Programme  
of the European Union

**Consumers, Health and Food  
Executive Agency**



## European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment



Co-funded by  
the Health Programme  
of the European Union

# Stakeholders

ExPO-r-Net is a 3.5 year project (03.2014 - 09.2017) to build and structure a European Reference Network for Paediatric Cancer (PaedCan ERN)



□ Project Coordination:  
CCRI /Vienna-AT



□ 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

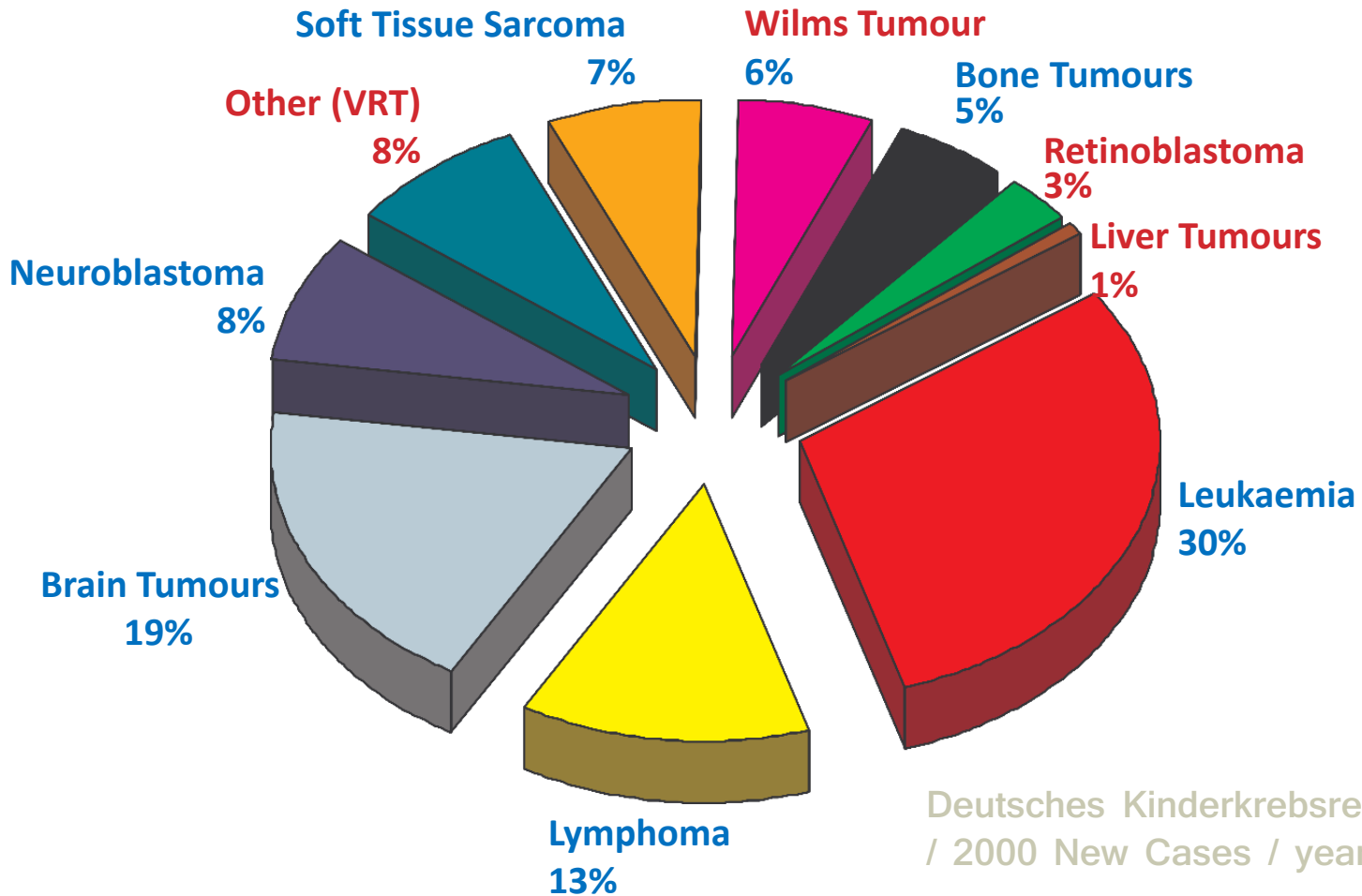




# Childhood Cancer



- Rare Disease Definition: 1 in 2000 [www.eurordis.org](http://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.



Deutsches Kinderkrebsregister Mainz  
/ 2000 New Cases / year



# ExPO-r-Net: PaedCan ERN Roadmap



- ❑ **Healthcare cooperation and resolving expert fragmentation**
- ❑ **Identifying special therapeutic needs** of young people with cancer requiring high expertise interventions with ECTG  
Examples: 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

**Guidance for Health Care Providers  
Increased Transparency for Affected Families**

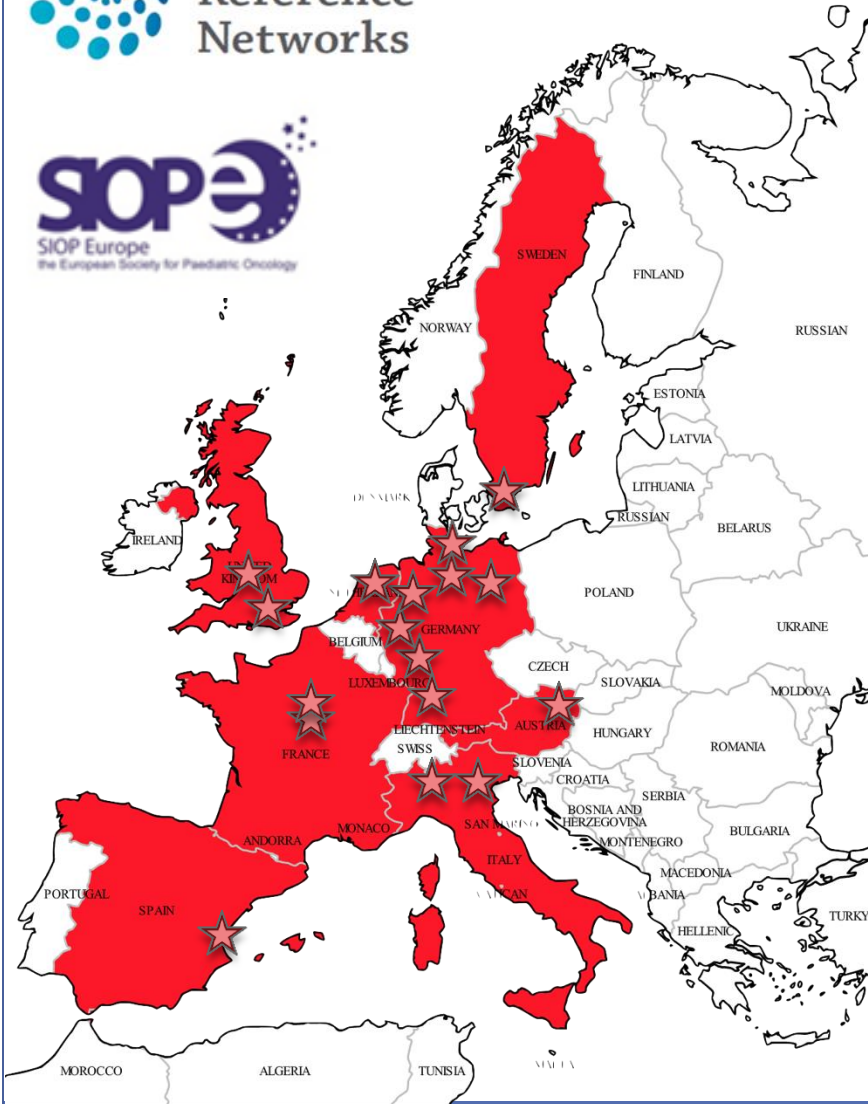
# European Clinical Trial Groups

## International Coordinating Sites (PI)

### Hubs of Coordination



European  
Reference  
Networks



#### ➤ Already in Expo-r-Net

- Acute Lymphoblastic Leukemia (ALL2009, IntreALL, Interfant, ALL-SCT)
- Brain Tumours ( div. entities)
- Ewing Sarcoma
- Hepatoblastoma
- LCH
- Lymphoma (NHL, Hodgkin)
- Neuroblastoma
- Osteosarcoma
- Soft Tissue sarcomas(CWS, EpSSG)
- Wilms Tumour
- Very Rare Tumours – paediatric age

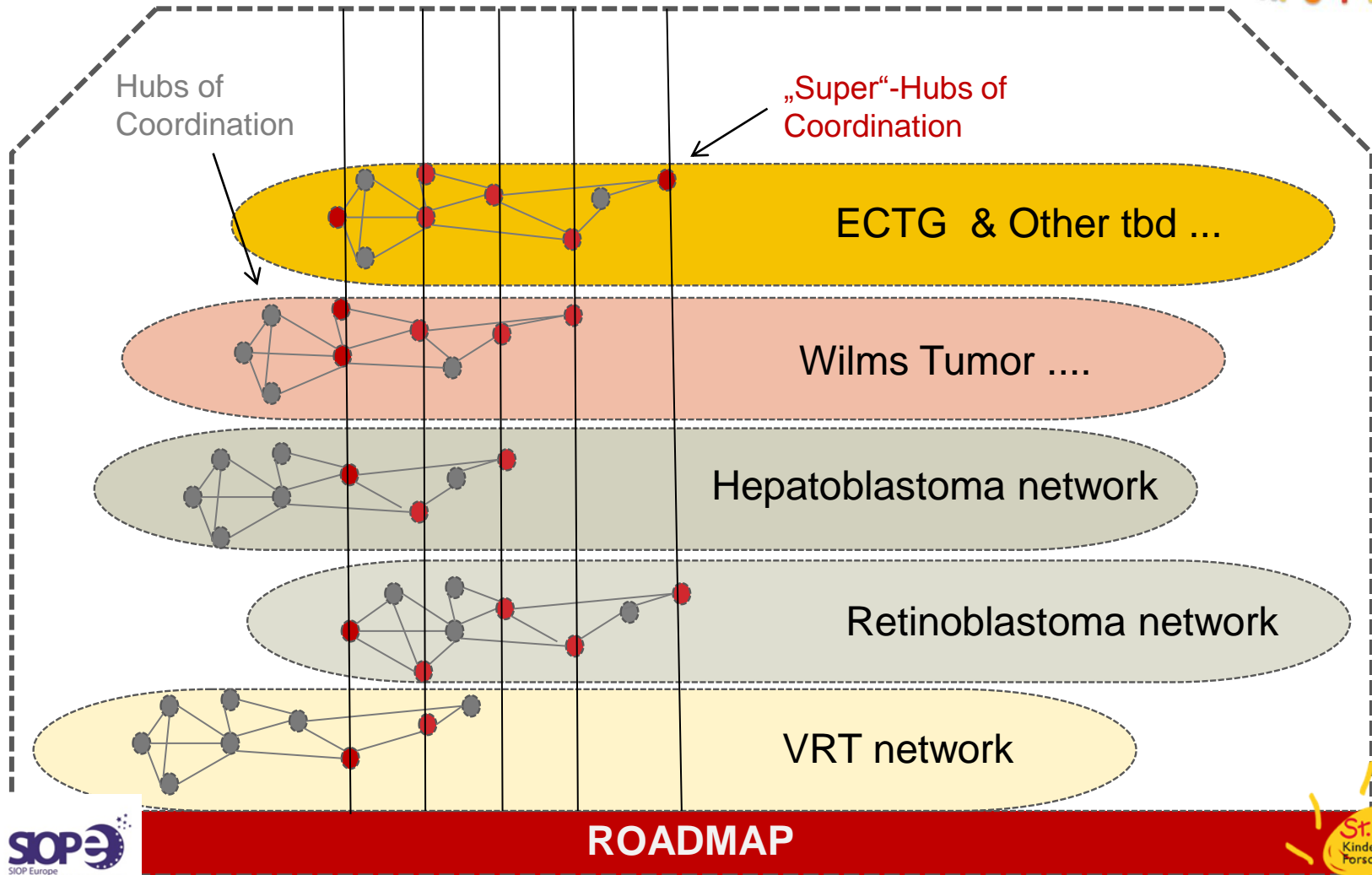
#### ➤ Invited

- AML
- Lymphoma Groups (NHL, Hodgkin)



Co-funded by  
the Health Programme  
of the European Union

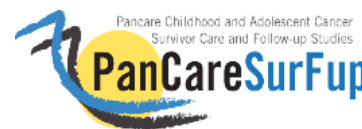
# PaedCan ERN







- 1) The Survivorship Passport is an innovative **patient-centered web platform** that provides a '**Patient Summary**' with relevant information on the medical history and treatment undergone by patients.
- 2) The **goal is to empower patients** and make them aware of the potential risks or late effects stemming from the previous diseases and treatments received.
- 3) It also includes **recommendations for a personalized long-term follow-up**, based on treatment history and **up-to-date clinical guidelines**, in collaboration with EU-Pancare experts.

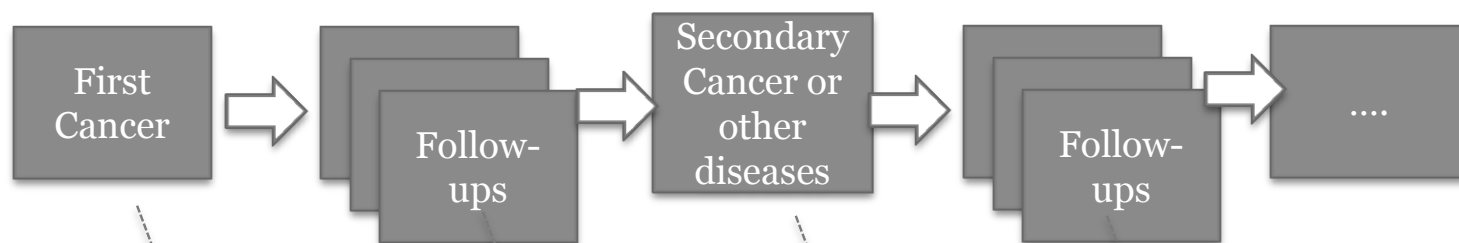


# Survivorship Passport: A life-long cancer-related patient-centered repository



**Life-long data preservation**

The long-term Cancer History



**Survivorship Passport Platform**



Survivorship Passport  
First Version



Survivorship Passport  
Second Version



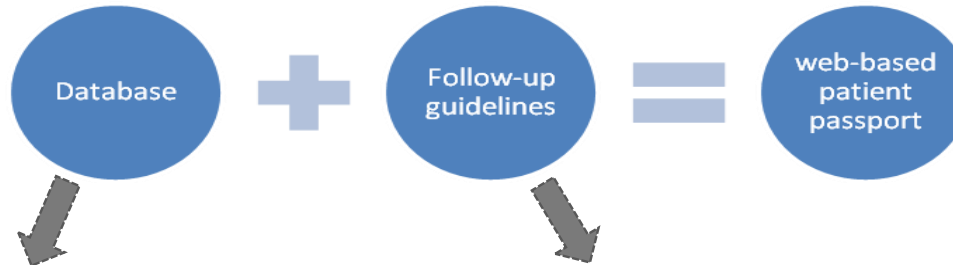
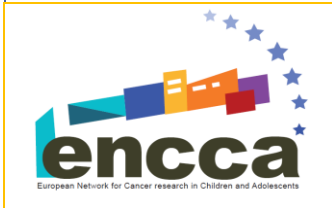
Survivorship Passport  
Third Version



Survivorship Passport  
Fourth Version



# 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  
variable  
s

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					
SMN breast cancer	Coronary / vascular disease				
	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)



may also gather medical images (e.g. Radiotherapy)

Survivorship Passport

Home > Registry Patients List > Patient's View > Radiation Therapy

Radiation Therapy

Patient's data

Holder	###	Patient Code	27	Registration Date	23/10/2015 (dd/mm/yyyy)	Date of birth	30/06/1984 (dd/mm/yyyy)
--------	-----	--------------	----	-------------------	-------------------------	---------------	-------------------------

Fields containing \* are mandatory. Please use . to insert decimal values.

Institution of treatment\* This Institution

Type of radiotherapy\* External beam

Please specify\* Photons of Xrays or gamma rays

Start year\* 1985

End year\* 1985

Site (1) Thoraco-Abdominal: Paraspinal

Dose\* 42 Gy

Boost? Yes

Boost site Boost to primary site

Type of radiotherapy\* External beam

Dose\* 54 Gy

Shielding?

Notes

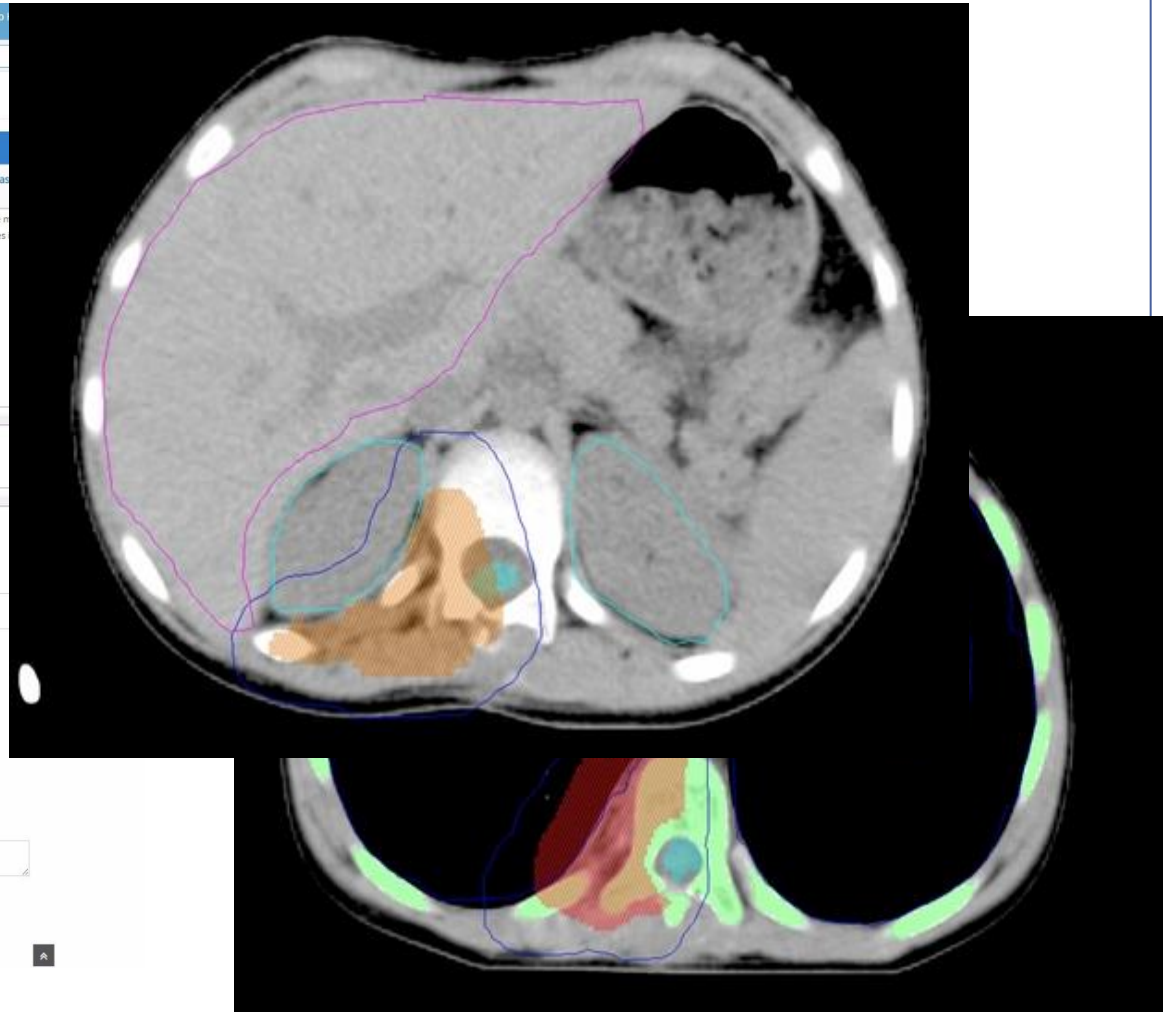
Insert other site?

Upload radiotherapy file (1) [Select file](#) fig1-codpat27.jpg

Upload radiotherapy file (2) [Select file](#) fig2-codpat27.jpg

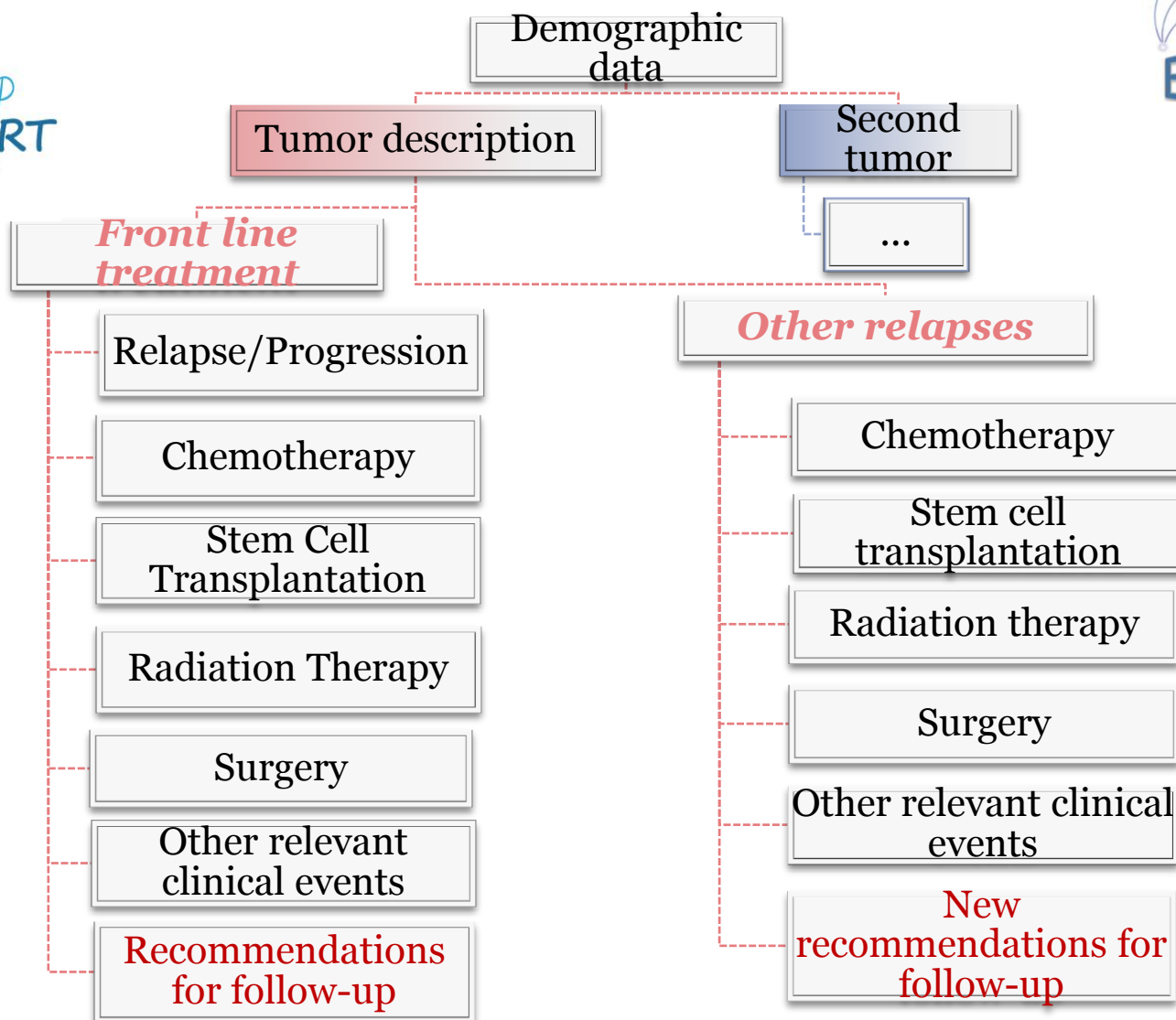
Notes

Save Send Clear form





# Survivorship Passport Data Schema



# Guideline example (English version)



## The risk of second malignant tumours

The risk of cancer increases for everyone as they get older. As a survivor of childhood cancer you may have a slightly higher risk of developing a cancer in adulthood compared to people of similar age in the general population. There are several factors that can affect this:

**Radiotherapy:** receiving radiotherapy, especially at a young age and in a large dose, increases the risk of developing a second cancer in the area of the radiation. These cancers are unlikely to develop until 10 years after treatment. The most common sites include the skin, the breasts, the bones, the brain, and the thyroid.

**Treatment with certain chemotherapy drugs:** there is a small risk of developing leukaemia after treatment with certain drugs e.g. etoposide, cyclo-phosphamide and drugs like adriamycin. If leukaemia does develop this is usually within 10 years of treatment.

**People who have a history of cancer in their family:** some patients have inherited gene changes (mutations) that increase the chances of getting a second cancer.

Inherited gene changes are quite uncommon and affect less than 10% of people diagnosed with childhood cancer. If the same or different cancers have occurred in several family generations, particularly at young ages, there may be a genetic link. A review of your family medical history will help decide if genetic counselling or testing is advisable.

## Breast Cancer Screening

[www.siope.eu](http://www.siope.eu)  
[www.pancare.eu](http://www.pancare.eu)  
[www.ighg.org](http://www.ighg.org)  
[encca.cineca.org/passport](http://encca.cineca.org/passport)



Yes, Go do it



It is reasonable to do  
More research required



It might be considered to be done  
More Research required



Stop, Don't do it



No specific recommendation can be made  
since further studies are needed



This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under the project ENCCA, grant agreement nr. HEALTH-F2-2011-261474 and the EiPO-Net Health Programme, grant agreement nr. 2013 12 07.

\*These recommendations are based on the article by R. L. Mulder et al published in Lancet Oncology in 2013: Mulder RLKremer LC, Hudson MM, Bhatia S, Lander W, Levitt G, Constant LS, Wallace WH, van Leeuwen FE, Ronckers CM, Henderson TO, Dayer M, Skinner R, Oeffinger KC; International Late Effects of Childhood Cancer Guideline Harmonization Group. Recommendations for breast cancer surveillance for female survivors of childhood, adolescent, and young adult cancer given chest radiation: a report from the International Late Effects of Childhood Cancer Guideline Harmonization Group. Lancet Oncol. 2013 Dec;14(13):e621-9.



WHAT DO I NEED TO KNOW?

Breast Cancer  
Screening

for survivors of  
childhood cancer

Name:

Passport nr.

survivorship  
passport



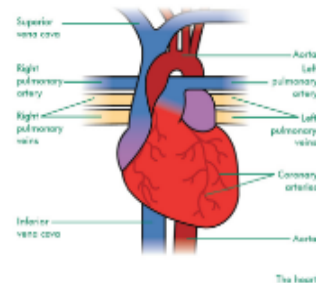
# Guideline example (German version)

## Manche Krebsbehandlung kann die Herzfunktion beeinträchtigen

Die Probleme können mehrere Jahre nach Therapieende auftreten.

**Diese Broschüre gibt eine Übersicht:**

- Wie das Herz funktioniert
- Wichtige Zeichen und Symptome für kardiale Beeinträchtigung
- Empfehlungen für regelmäßige kardiologische Untersuchungen für jene Patienten, die bei ihrer Krebstherapie potentiell herzscheidigende Medikamente erhalten haben.



Das **Herz** ist ein kräftiger Muskel, der das Blut durch den ganzen Körper pumpt. Das Blut liefert Sauerstoff und Nährstoffe in den Körper und transportiert Kohlendioxid und Abfallprodukte ab. (siehe Abbildung).

Das **Blut** wird durch zwei Gefäße vom Herz in den Körper gepumpt: die Aorta und die Pulmonalarterien. Es wird in zwei großen Gefäßen wieder zurück zum Herzen geführt: die obere und untere Hohlvene.

Das **Herz** ist in vier Kammern unterteilt:

Den rechten und linken Vorhof, sowie die rechte und linke Herzkammer. Durch die Vorhöfe kommt das Blut ins Herz und die Kammern pumpen es wieder aus dem Herzen.

Es gibt 4 Herzklappen, welche den Blutfluß in eine Richtung lenken.

Die Herzfrequenz, in der das Herz schlägt, wird von einem autonomen Nervensystem im Herzen gesteuert. Die Kraft mit der das Herz Blut in den Körper pumpt, ist von der "Gesundheit" des Herzmuskels abhängig und der Funktion der Herzklappen.

Schließlich wird das Herz von einer schützenden Hülle, dem Herzbeutel umgeben.

## Kardiomyopathie Vorsorgeuntersuchungen

[www.siope.eu](http://www.siope.eu)

[www.pancare.eu](http://www.pancare.eu)

[www.ighg.org](http://www.ighg.org)

[encca.cineca.org/passport](http://encca.cineca.org/passport)



Ja, soll durchgeführt werden, wird empfohlen



Es ist empfehlenswert, zur eindeutigen Empfehlung sind weitere Studien noch nötig



Es ist möglicherweise empfehlenswert/sinnvoll



Nicht empfohlen



Keine spezielle Empfehlung, zukünftige Studien sind diesbezüglich nötig



Die Finanzierung dieses Projektes erfolgte in Rahmen folgender EU-Projekte: European Union's Seventh Framework Programme for research, technological development and demonstration under the project ENCCA, grant agreement nr. HEALTH-12-2011-261474 and the ExPa-R-Net Health Programme, grant agreement nr. 2013 12 07

Diese Empfehlungen entsprechen folgender Publikation:  
Mulder RL, Kremer LC, Hudson MM, Bhatta S, Landier W, Levitt G, Constine LS, Wallace WH, van Leeuwen PE, Ronckers CM, Henderson TO, Dwyer M, Skinner R, Offinger KC: International Late Effects of Childhood Cancer Guideline Harmonization Group. Recommendations for breast cancer surveillance for female survivors of childhood, adolescent, and young adult cancer given chest radiation: a report from the International Late Effects of Childhood Cancer Guideline Harmonization Group. *Lancet Oncol.* 2013 Dec;14(13):e621-9



WAS IST FÜR MICH WICHTIG ZU WISSEN?

Kardiomyopathie  
Vorsorgeuntersuchungen



für Erwachsene nach  
Krebserkrankungen  
im Kindesalter

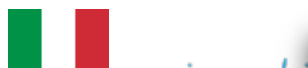
survivorship  
passport



Name:

Pass nr.





## RIEPILOGO DEL TRATTAMENTO

Questo "Passaporto del guarito" ("Passport of the survivor") è un riassunto dei trattamenti ricevuti per la sua cura e la sua necessità.

Marie DOE

### DATI PERSONALI

Data di nascita  
Città di residenza  
Tipo di documento identificativo  
Contatto appartenente a  
E-mail

### PRIMO TUMORE

### DIAGNOSI

Data di diagnosi  
Istituto  
Alto rischio

### ALTRE MALATTIE

Sindromi genetiche predisponenti  
Altri quadri clinici, associati a  
Altri quadri clinici, non associati

### TRATTAMENTO DI PRIMA LINEA

Il trattamento è stato eseguito  
Lista delle principali terapie

Progressione/recidiva durante



## 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 the treatments you received. This document does not replace the medical record that is always available at our center."

Marie DOE

Passport Number: IT12015092121

### PERSONAL DATA

Date of birth	15/07/1993	Gender	Female
Place of birth	LONDON, ENGLAND, UNITED KINGDOM		
Identification Document type	National ID Card	Number	UK120101277
Contact belonging to	Survivor		
E-mail	john.doe@example.com		

### FIRST TUMOR

### DIAGNOSIS

Date of diagnosis	07/02/2007
Institution	Test Sistema
Cancer category	9650/3 - Hodgkin lymphoma, NOS
High risk	No

### OTHER DISEASES

Hereditary Cancer Predisposition Syndrome	No
Other medical conditions, cancer associated	No
Other medical conditions, not cancer associated	No

### FRONT LINE TREATMENT

The treatment has been executed following	Guidelines	
Summary of major treatments	Chemotherapy	Yes
	Stem Cell transplantation	Yes
	Radiotherapy	Yes
	Major Surgery	Yes

Progression/relapse during frontline treatment

Yes



## The Survivorship Passport: 2 sides of the same coin



### Care

- Empowerment of survivors
- Risk adapted personalized follow-up
- Homogeneous follow-up
- Guidelines available to survivors and GP
- Appropriate use of NHS resources



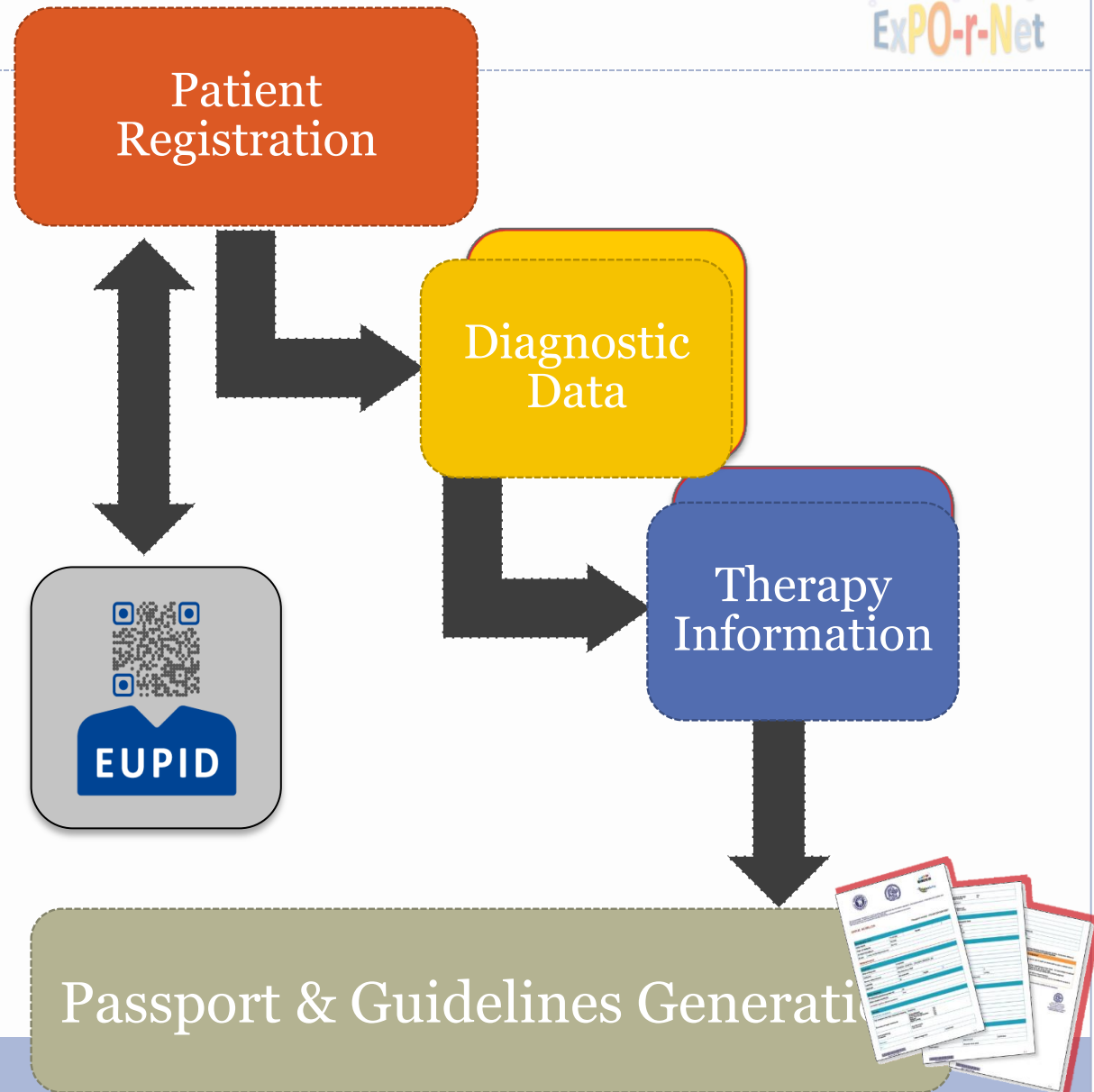
### Research

- Early identification of «epidemic» of emerging rare events
- Identification of risk factors
- Move from «cure at any price» to «cure at least price»
- Design of new treatment strategies

# Survivorship Passport Data Flow



- A. Clinician registers the patient in the Patient Registration form
- B. During the registration process, the system requests the EUPID code for the Patient
- C. In the Diagnostic Data area the clinician can collect all the relevant clinical information
- D. Therapy Information are important for the generation of guidelines
- E. The system generates the Passport and related Guidelines



# Already available Tools from ENCCA



## ❑ EUPID - European Unified Patient IDentity Management Service

- [www.eupid.eu](http://www.eupid.eu) (beta)



## ❑ Survivorship Passport – Patient Summary



R. Ladenstein, M. Schrappe, K. Pritchard-Jones, Z. Dobai, S. Essiaf, P. Kearns, *et al.*, "ENCCA - EUROPEAN ACTIVITIES AND ACHIEVEMENTS WITH POTENTIAL INTEREST OUTSIDE OF EUROPE," *Pediatric Blood & Cancer*, vol. 62, pp. S202-S202, Nov 2015.

# EUPID Concept



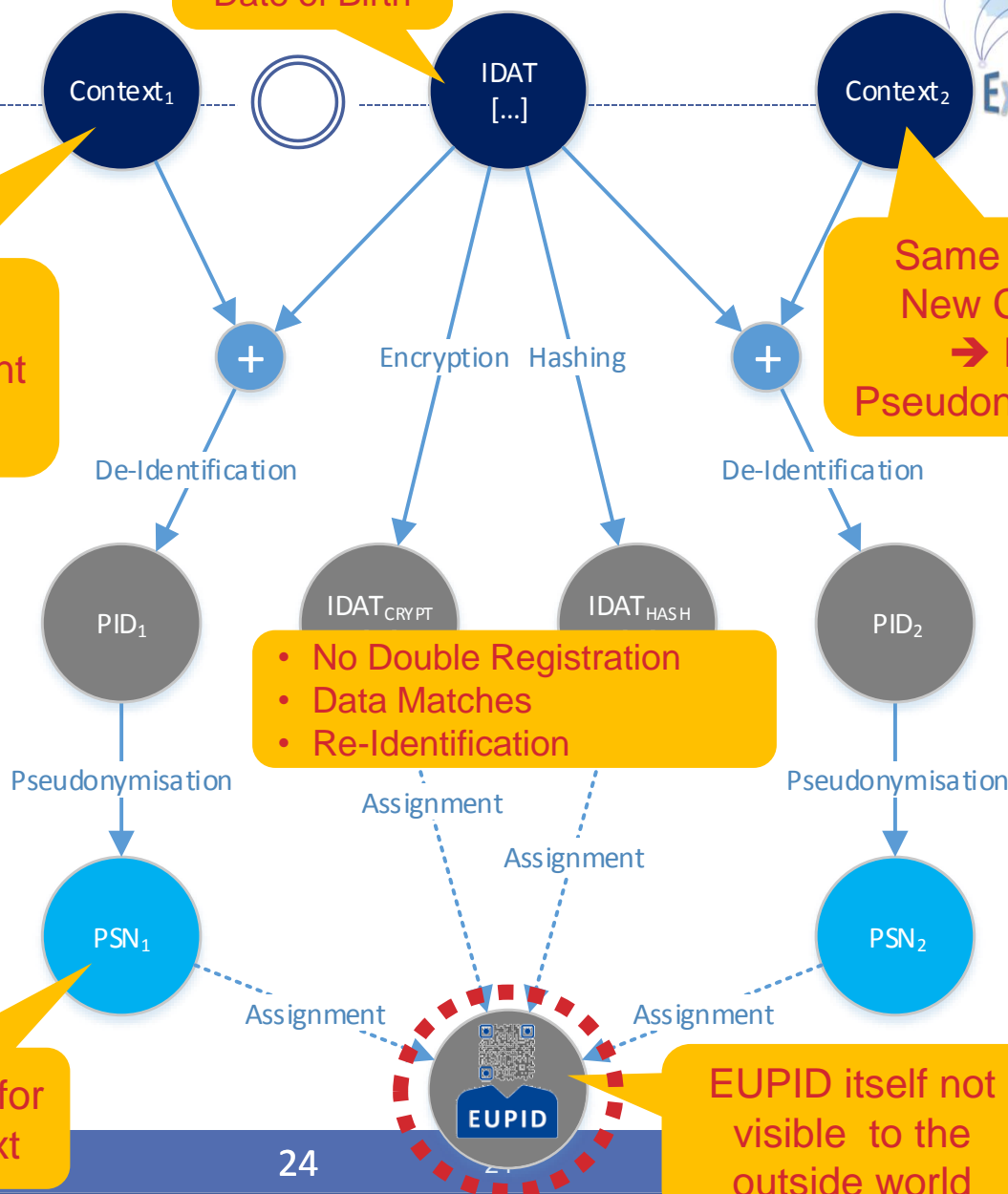
Given Name  
Surname,  
Date of Birth

Each Context  
needs 1 Informed Consent  
(i.e Trial A)

Same Patient  
New Context  
→ New  
Pseudonym PSN<sub>2</sub>

**IDAT** Identity Data  
**IDAT<sub>CRYPT</sub>** Encrypted Identity Data  
**IDAT<sub>HASH</sub>** Hashed Identity Data  
**MDAT** Medical Data  
**PID** de-identified context-specific Patient Identifier  
**PSN** Pseudonym  
**EUPID** European Unified Patient Identifier

■ Input (GUI)  
 ■ accessible (Output)  
 ■ inaccessible (internal)



• No Double Registration  
 • Data Matches  
 • Re-Identification

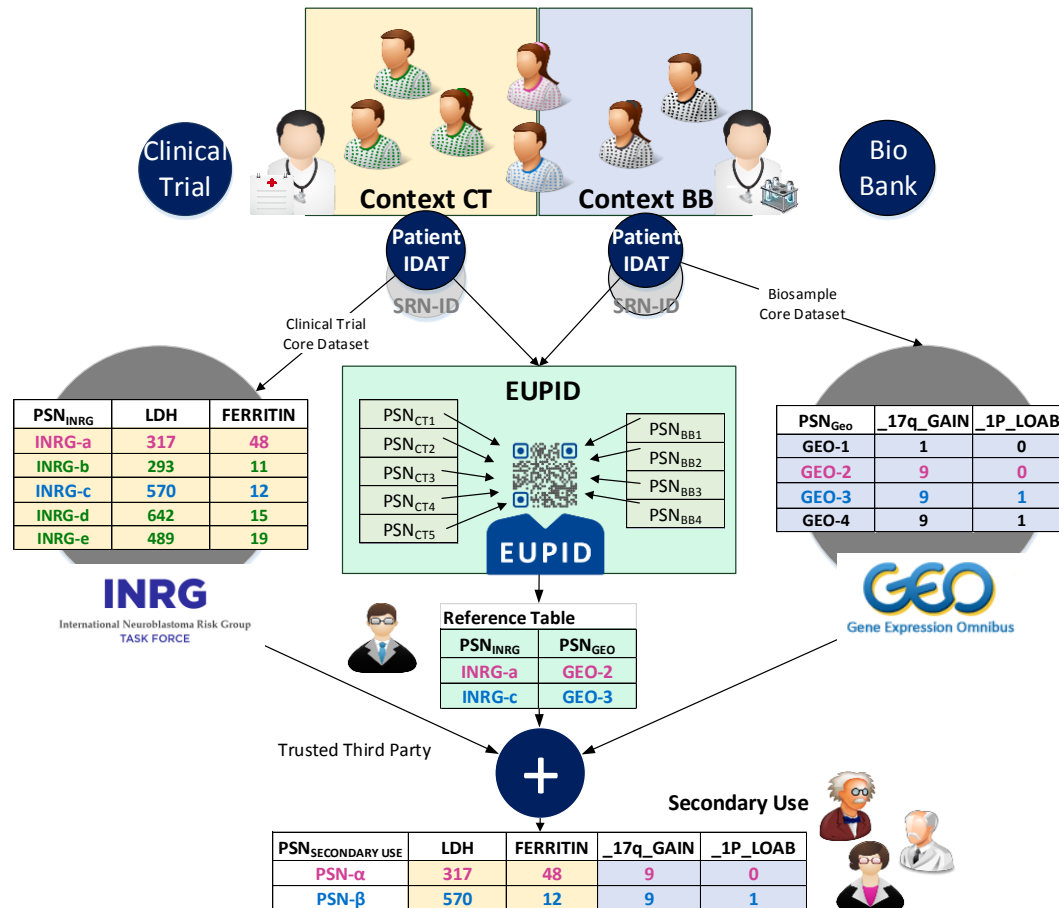
Pseudonym for  
this Context

EUPID itself not  
visible to the  
outside world



# Secondary Use of Data

## Pilot Neuroblastoma Data Integration



**KEY and UNIQUE to EUPID:**  
**No central personal data storage in Europe!**  
*Personal Data stays with Health Care Providers only*

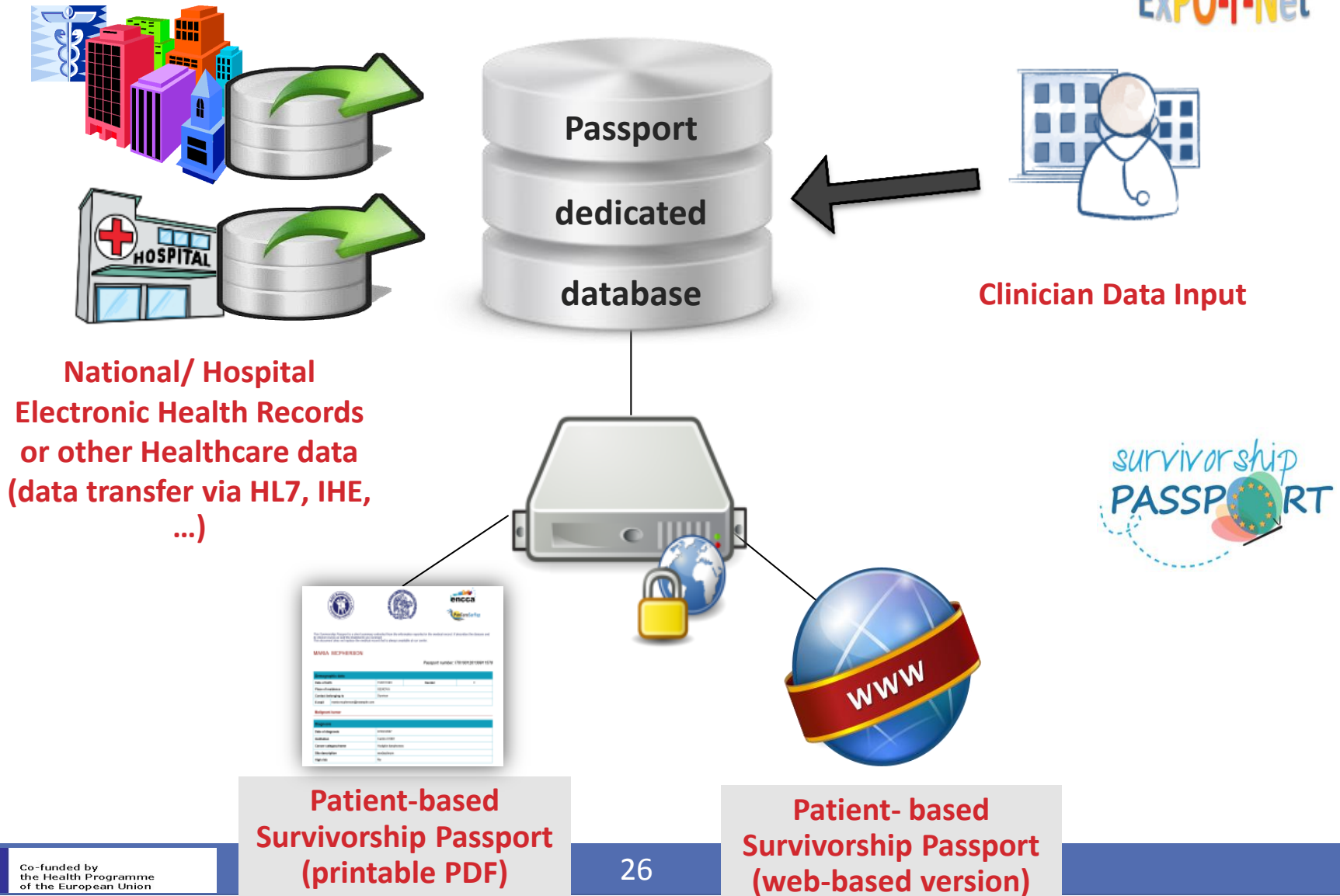


eHEALTH  
2016

Co-funded by  
the Health Pr  
of the Europe

H. Ebner, D. Hayn, M. Falgenhauer, M. Nitzlnader, G. Schleiermacher, R. Haupt, *et al.*, "Piloting the European Unified Patient Identity Management (EUPID) Concept to Facilitate Secondary Use of Neuroblastoma Data from Clinical Trials and Biobanking," *Stud Health Technol Inform*, vol. 223, pp. 31-8, 2016.

# The Survivorship Passport Data Flow



# Survivorship Passport Data Access: Future



Patient will have the possibility to view and share his own data during lifetime



WEB



EUPID

Legenda



View data



Update data



Patients

National  
Authorities



Oncologists,  
GPs,.



Data Input  
(Hospital)



# Future planned Developments



## ❑ 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

## ❑ SU-PP Concept part of Austrian National Cancer Plan

- Implementation with the Austrian electronic health records
- European eHealth based long term follow up and advisory health surveillance instrument solution for a moving population



# Long Term Follow Up Integration in new Clinical Trials



- Identification of Core data set for LTFU (eHealth compatible)
- Integration of LTFU diagnostic test in clinical trials
- Data linkage of data bases and LTFU registries via EUPID
- Secondary Use of data via eHealth /Research platform integrating the eHealth Survivorship Passport



# ExPO-r-Net: Key Benefits



- ❑ **Improved visibility and access to expert care and advice in Europe:**  
A 'roadmap' of centres to allow medical teams to find expert sites for given conditions for advice and patient referral if indicated
- ❑ **Information on cross-border treatment modalities:** in another EU –Member State accessing healthcare or advice received and reimbursement for advice
- ❑ **Possibility to be treated at home or abroad:** Mechanisms to facilitate movement of information and knowledge rather than patients whenever possible;
- ❑ **Progress in instituting virtual late effects centre:**  
incl. operationalising Survivorship Passport
- ❑ **Elevated standards of treatment and care across all of Europe**

# PaedCan ERN



European  
Reference  
Networks



## THANK YOU!



The project ExPO-r-Net has received funding from the European Union in the framework of the Health Programme (2008-2013), grant agreement nr. 2013 12 07. The content represents the views of the author and is his sole responsibility and it can in no way be taken to reflect the views of European Union bodies. The European Commission and/or Chafea do not accept responsibility for any use that may be made of the information it contains.





# PaedCan ERN

## ExPo-r-Net Roadmap

### Hepatoblastoma

#### □ Background

- **Annual hepatoblastoma incidence:** 1-1,5 case / million, thus expected number of hepatoblastoma cases annually in Europe is 120-180
- **Childhood Liver Tumours Strategy Group SIOPEL:** European platform with 211 members and global partners to discuss paediatric liver tumours
- **SIOPEL therapy Guidelines:**
  - Standard risk SIOPEL3 cisplatin monotherapy
  - High risk non-metastatic SIOPEL3 SuperPLADO
  - High risk metastatic SIOPEL4 dose intensive cisplatin
  - HCC – in preparation





# PaedCan ERN

## ExPo-r-Net Roadmap

### Subentity Hepatoblastoma

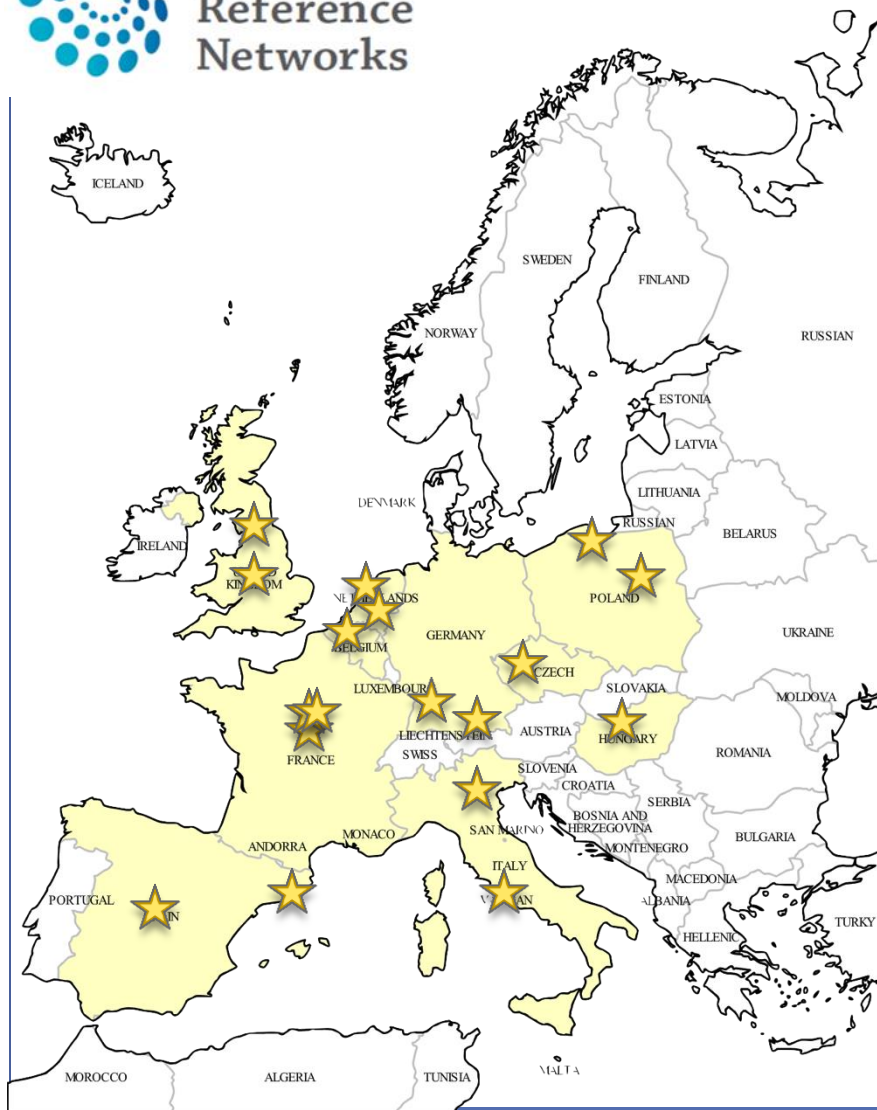
#### □ Impact

- Network of European centres of expertise in the treatment of paediatric liver tumors
- **Access to equipment and experience in unique treatment modalities:**
  - Liver transplantation (LTX)
  - Chemoembolization (HACE)
  - Radiofrequency ablation (RFA)
  - Complicated liver resections with vascular reconstructions
- Fully operational Virtual Consultation Forum
- Standardized consultation and referral criteria
- European state-of-the art in hepatoblastoma



# Hepatoblastoma

## Hubs of Coordination



	Country	Institute, Location
1	<b>Belgium</b>	Cliniques Universitaires Saint-Luc, Brussels
2	<b>Czech Republic</b>	Motol Children's Hospital, St. Charles University, Prague
3	<b>France</b>	Institut Gustave Roussy (IGR) , Villejuf
4	<b>France</b>	Institut Curie, Paris
5	<b>France</b>	University of Paris, Kremlin-Bicetre
6	<b>France</b>	Hopital Necker Enfants Malades, Paris
7	<b>Germany</b>	University of Munich
8	<b>Germany</b>	University of Tuebingen
9	<b>Hungary</b>	Semmelweis University Budapest
10	<b>Italy</b>	Azienda Ospedaliera di Padova (AOPD)
11	<b>Italy</b>	Ospedale Pediatrico Bambino Gesù, Rome
12	<b>Netherlands</b>	VU University Medical Center, Amsterdam
13	<b>Netherlands</b>	Dept. Of Pediatric Surgery center in Utrecht
14	<b>Poland</b>	The Medical University of Gdansk
15	<b>Poland</b>	Memorial Children's Hospital, Warsaw
16	<b>Spain</b>	Hospital Universitario Vall d'Hebron
17	<b>Spain</b>	Hospital Carlos III (Madrid), Madrid La Paz
18	<b>UK</b>	Birmingham Children's Hospital (UOB)
19	<b>UK</b>	Leeds Children's Hospital



# SIOPEL

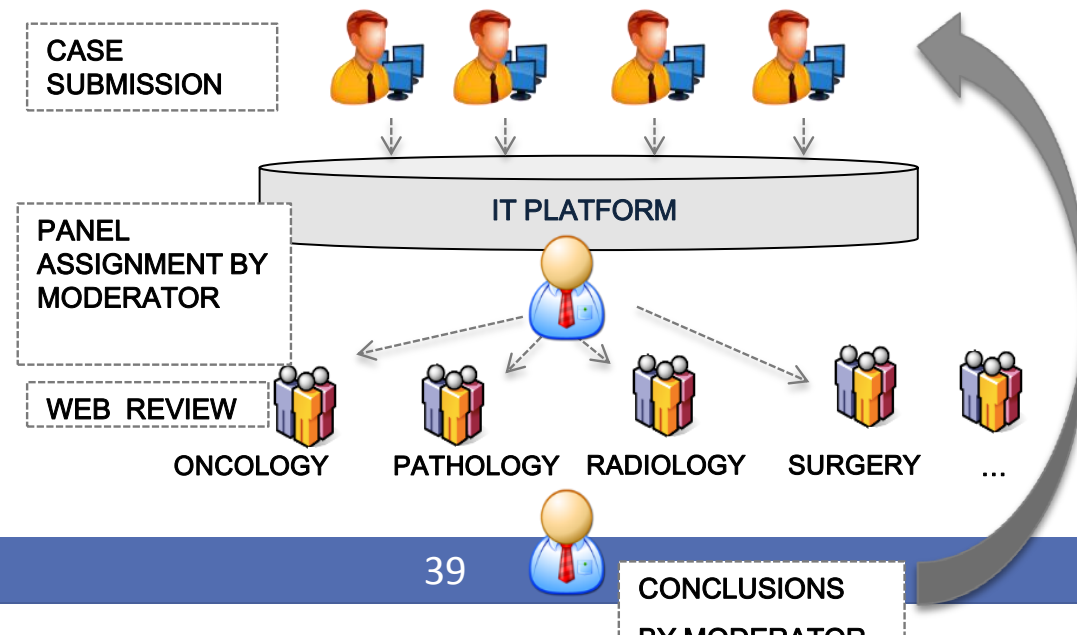
## Virtual Case Consultation system

User oriented web portal for virtual advice  
developed and supported by CINECA, Italy

### Advantages

- Provide access to global expertise to support clinicians in managing challenging cases, particularly in rare diseases
- Opportunity to update clinicians on new developments in diagnosis, risk stratification and treatment approaches
- Cases storage for training purposes

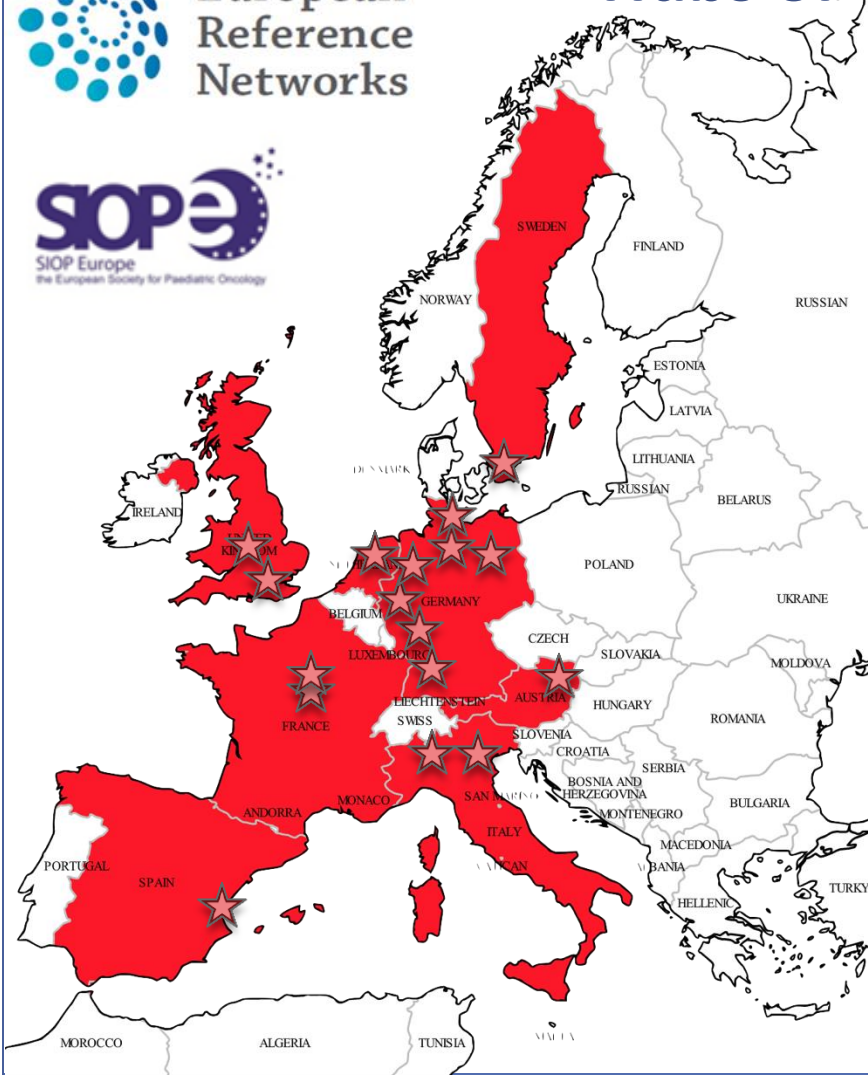
### Workflow



# European Clinical Trial Groups

## International Coordinating Sites (PI)

### Hubs of Coordination



Country	Institute, Location
1 Austria	St. Anna Kinderspital (SAK)/Children's Cancer Research Institute (CCRI), Vienna
2 France	Institut Gustave Roussy (IGR) , Villejuf
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)



# European Clinical Trial Groups International Coordinating Sites (PI) Hubs of Coordination



European  
Reference  
Networks



## ➤ Already in Expo-r-Net

- Acute Lymphoblastic Leukemia (ALL2009, IntreALL, Interfant, ALL-SCT)
- Brain Tumours ( div. entities)
- Ewing Sarcoma
- Hepatoblastoma
- LCH
- Lymphoma (NHL, Hodgkin)
- Neuroblastoma
- Osteosarcoma
- Soft Tissue sarcomas(CWS, EpSSG)
- Wilms Tumour
- Very Rare Tumours – paediatric age

## ➤ Invited

- AML
- Lymphoma Groups (NHL, Hodgkin)



Co-funded by  
the Health Programme  
of the European Union

# **Pediatric Haematology Oncology Clinical Centres in European Countries with Low Health Expenditure Rates (LHEAR)**



## **Preparation of a checklist enabling self-assessment by treatment centres of their compliance with the European Standards**

- Identification of centres in Central/Eastern Europe, which meet specified criteria to fulfil the Standards of Care
- They will become visible internationally and may in the future interact with “hubs of coordination” via virtual tumour boards.
- These identified centres should be able to do baseline care for the patients, with help and advice from tumour boards



# LHEAR Countries in Europe



- ❑ >2000 U\$: Czech Rep., Slovakia, Slovenia
- ❑ 1400 – 1800 U\$: Croatia, Estonia, Hungary, Lithuania, Poland
- ❑ 1100-1200 U\$: Bulgaria, Latvia, Serbia
- ❑ < 1000 U\$: Belarus, Bosna-Herzegovina, Macedonia, Romania, Ukraine





# Self Assessment Questionnaire based on the Standards of Care Requirements in PHO






## ❑ “Assessment test run”

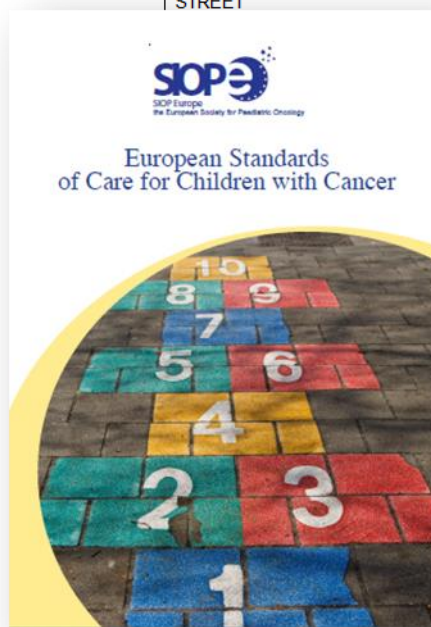
- UCL London
- IGR Villejuif
- Erasmus Rotterdam
- Milano
- Kiel

## ❑ LHEAR Countries

- Sofia, Bulgaria
- Bucharest, Romania

   Co-funded by the Health Programme of the European Union	<b>SELF-ASSESSMENT QUESTIONNAIRE FOR PAEDIATRIC HAEMATOLOGY/ONCOLOGY CENTRES</b> <b>STANDARD OF CARE PROFILE</b>
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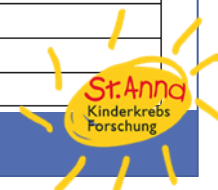
CONTACT DETAILS CENTRE	
INSTITUTION (coordinating centre)	
ACRONYM OF THE INSTITUTION	
COUNTRY	
CITY	
STREET	



  
 SOPe Europe  
 the European Society for Paediatric Oncology  
**European Standards  
 of Care for Children with Cancer**

NOTES
<p>Complete the questionnaire by marking with a cross the box where applicable or by writing in the box. Please save the file and assign as name of the file the city and acronym of the centre.</p> <p>To evaluate the structural services, the available human resources and the equipment of the centre. Therefore, it is very detailed; Please note that an individual PHO centre, does not necessarily need to have all components. It is important to complete the form accurately to enable the evaluation.</p> <p>The form should be signed and dated by .....to.....</p>

Activities <sup>1</sup>		Possible remarks
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
Immunology	<input type="checkbox"/>	
Other <sup>3</sup>	<input type="checkbox"/>	

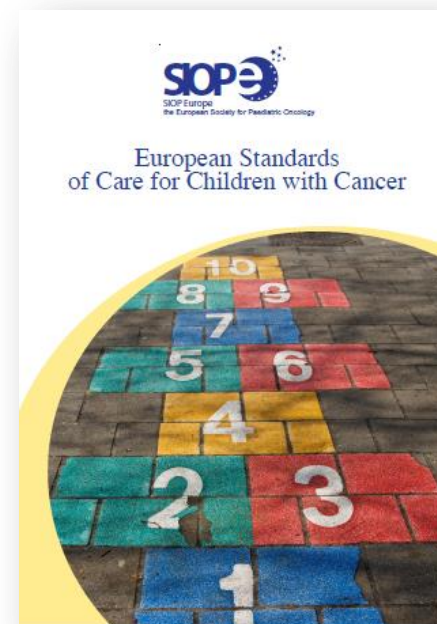


# ExPO-r-Net: Patients, Survivors at Heart



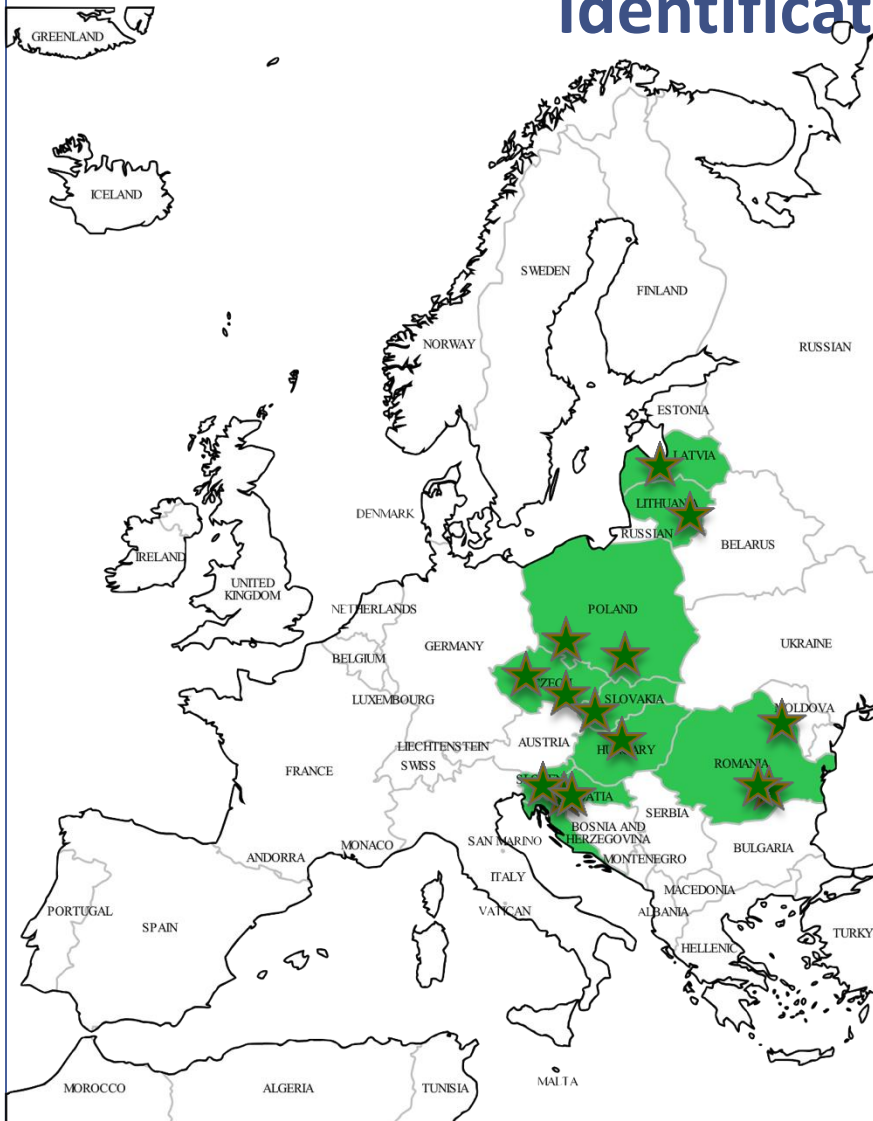
**Childhood Cancer International Europe (CCI Europe)** is instrumental in feeding the needs of childhood cancer parents organisations and survivor groups to the project.

- **Example:** Participation to questionnaires and site visits to centres with the potential to link to the PO-ERN based on European Standards of Care for Children with Cancer .



# LHEAR – National Centres

## Identification ongoing



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

Planned after site evaluation:

- Affiliation of LHEAR Hocs with PaedCan ERN Hocs as needed
  - For VTB
  - For optional CBHC referrals

