



European  
Reference  
Network

for rare or low prevalence  
complex diseases

 Network  
Paediatric Cancer  
(ERN PaedCan)



# ERN PaedCan and Standards of Care: Supporting equal Access

Ruth Ladenstein

SIOPE Board Member & ERN PaedCan Coordinator

CCRI, Vienna, Austria



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# ERN PaedCan: Vision



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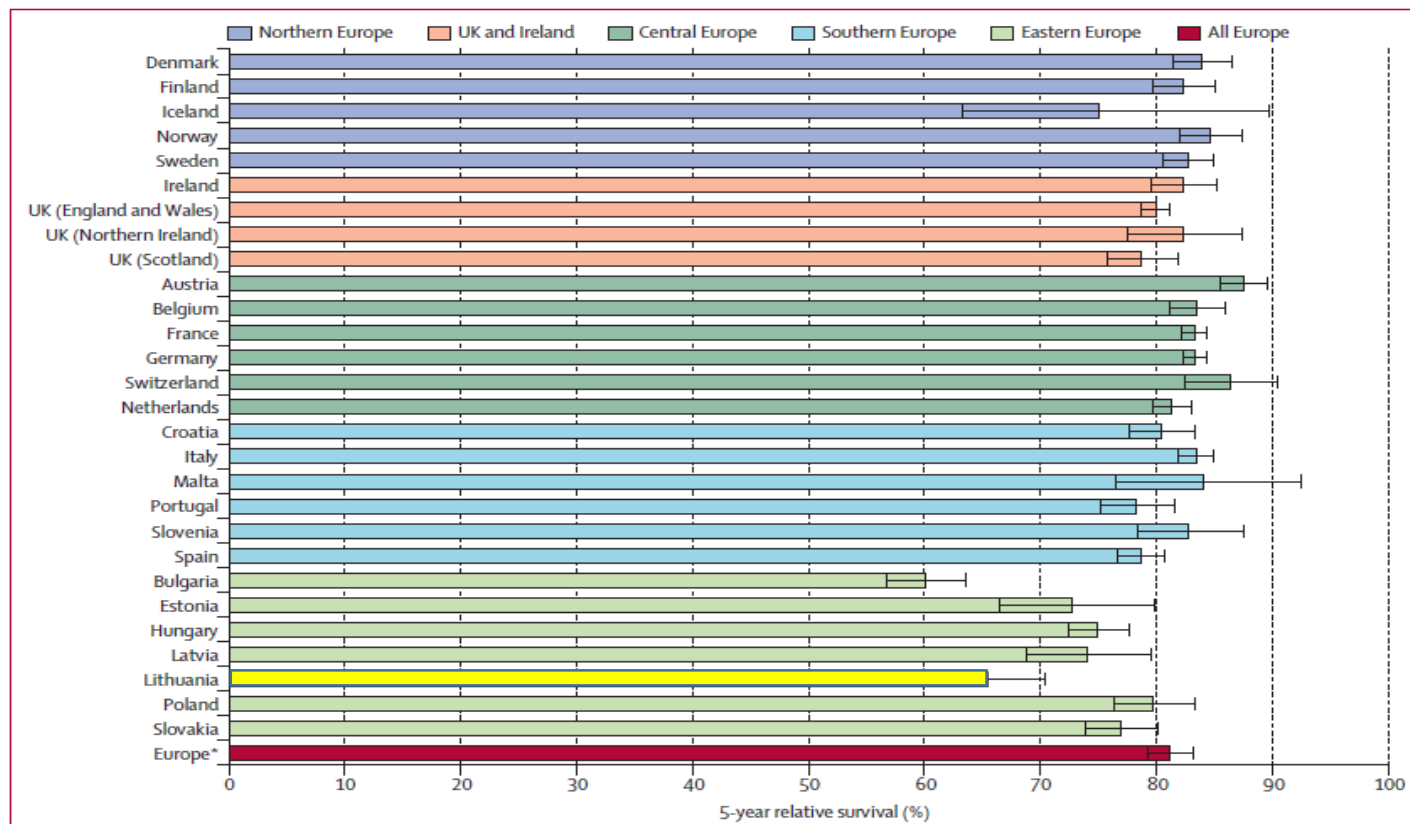
- Equal and possible best paediatric cancer care and outcomes no matter where in Europe children live
- EC Vision on ERNs: A sustainable European Structure!



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# Five year overall survival of children treated for solid tumors (non-CNS) in 2000-2007



Gatta et al. Lancet Oncol. 2014



# ERN PaedCan: Mission

## 1) Reduce inequalities of childhood cancer outcomes across Member States

- By supporting access to up to date diagnostics and treatments by facilitating the exchange of expertise and knowledge

## 2) Implementation of Virtual Tumour Boards

- Medical expertise and knowledge travels rather than patients

## 3) Proportionate & appropriate Cross-Border Healthcare

- to unite the best specialists across Europe to tackle complex or rare paediatric cancer conditions that require highly specialized interventions and a concentration of knowledge and resources.

# ERN PaedCan Members

2017

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



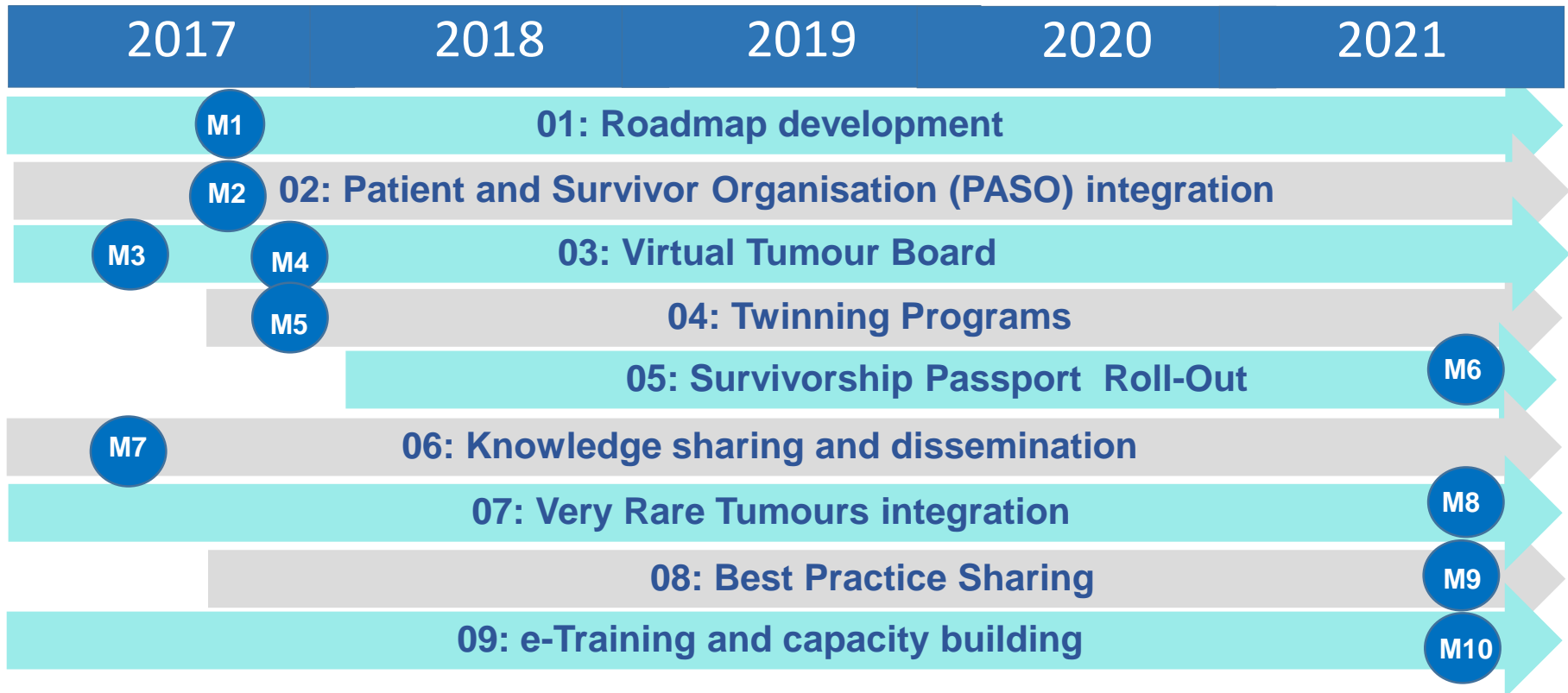
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ERN PaedCan Kick-Off Meeting 29<sup>th</sup> June 2017





# ERN PaedCan Implementation Plan





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# The Strength of Collaboration & Shared 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/>



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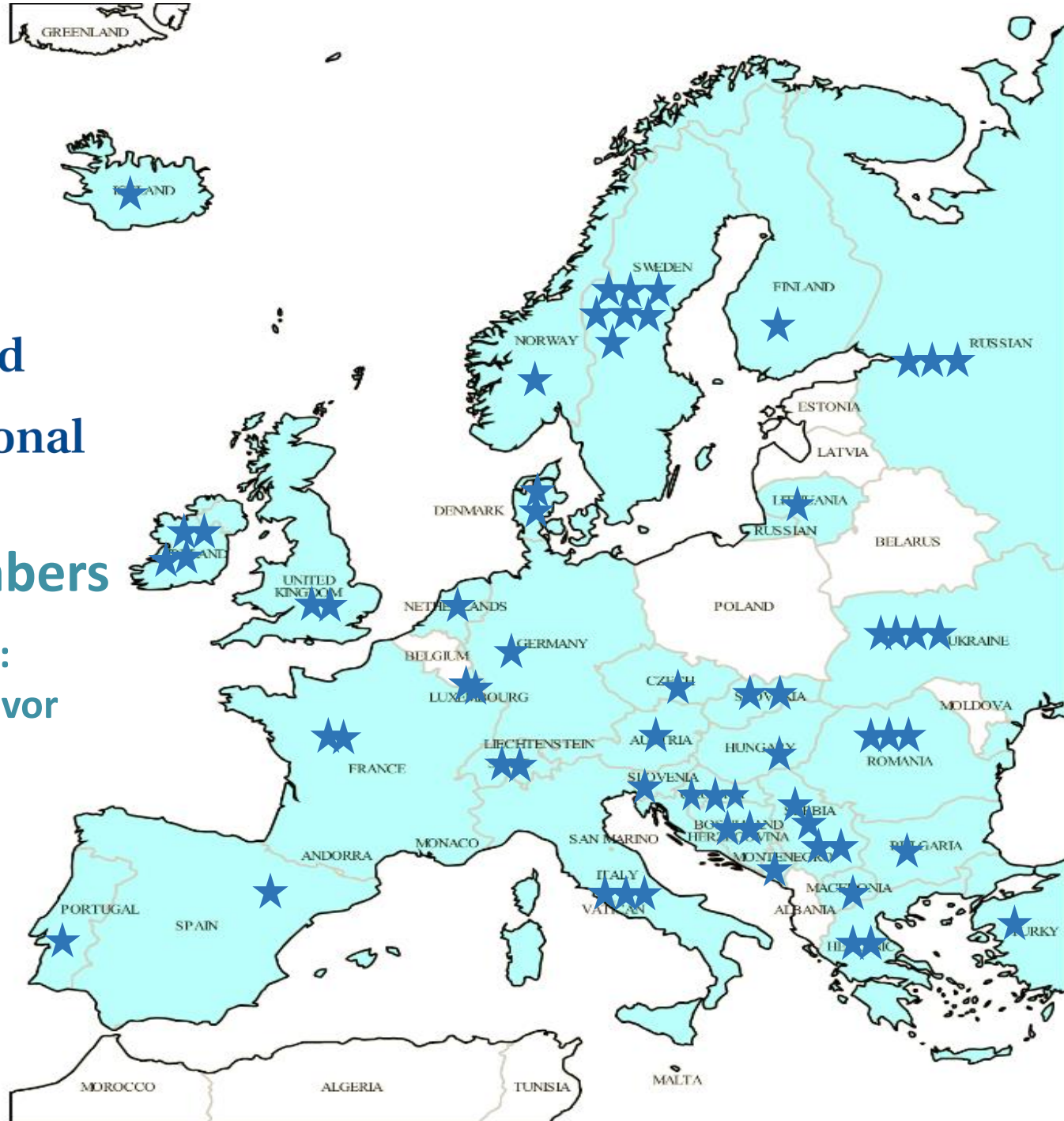




## CCI Europe Members

As identified in 2017:

- 66 Parent & Survivor Organizations
- 33 Countries





**“Kicking – off” is only the first step on a long journey !**



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## 3<sup>rd</sup> ERN Conference, Vilnius 2017

Inauguration of 24 European Reference Networks, March 9-10<sup>th</sup>



**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



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# New Mission Targets

## Stakeholder Needs & Sustainability



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# Innovation in Care Models

## ■ European Standard of Care ✓

- Quality care parameters of hospital settings, staffing including psychosocial care [Kowalczyk et al., Eur J Cancer 2016]

## ■ Standard of Treatments – ECTG ✓

- Standard reflected in the ECTG- SIOPE - ERN PaedCan Road Map
- Tumour entity specific guidelines

## ■ Standard for Follow Up Care

- PanCare guidelines

👉 **Guideline development is a work-intensive, lengthy process currently “in-kind” experts time**

👉 **To establish European Quality Care Models :  
Non- competitive European Funding for high- quality guideline  
development is a need !**





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# 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**

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



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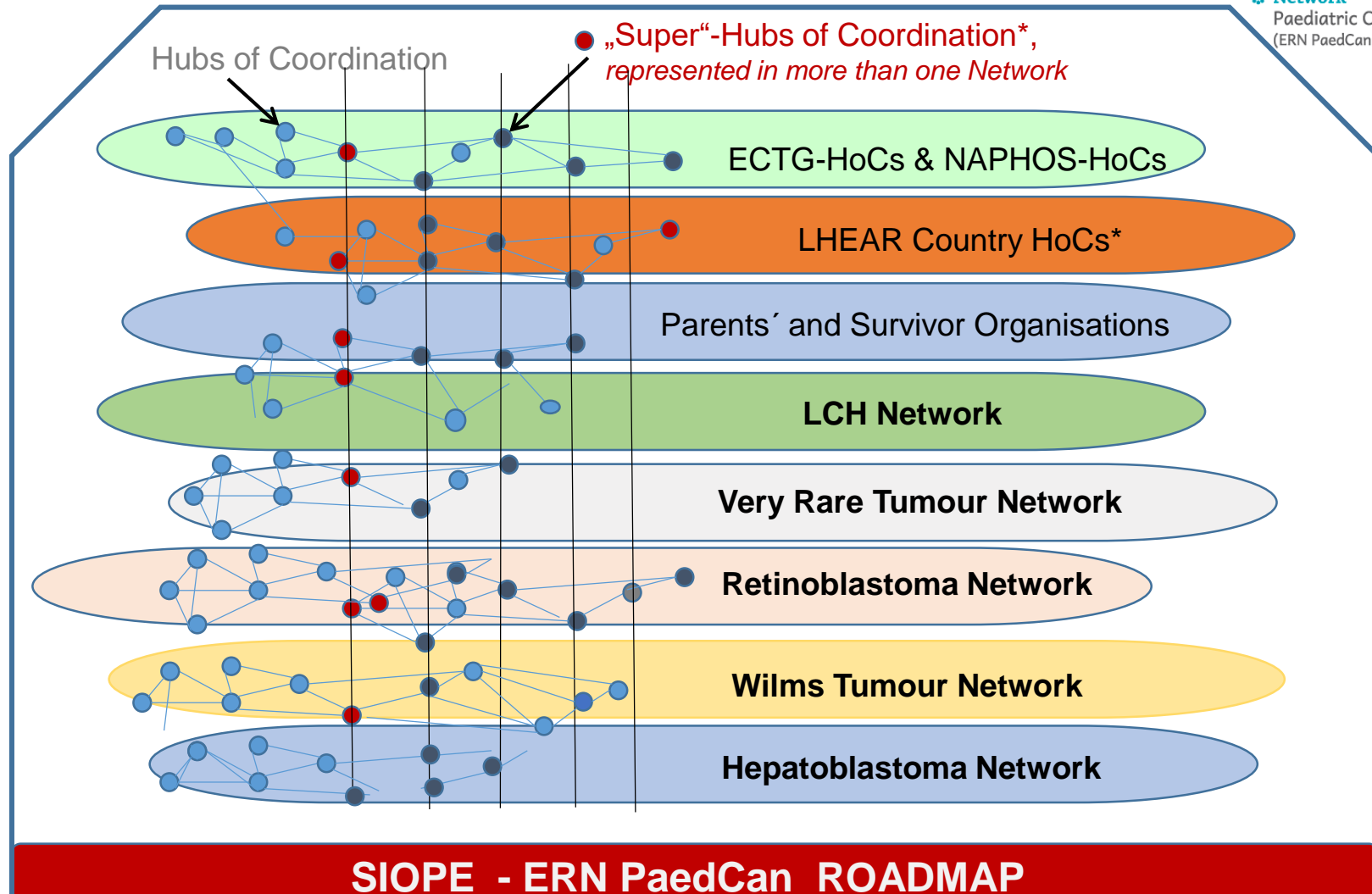


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# Current Roadmap Layers



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# One example: Retinoblastoma

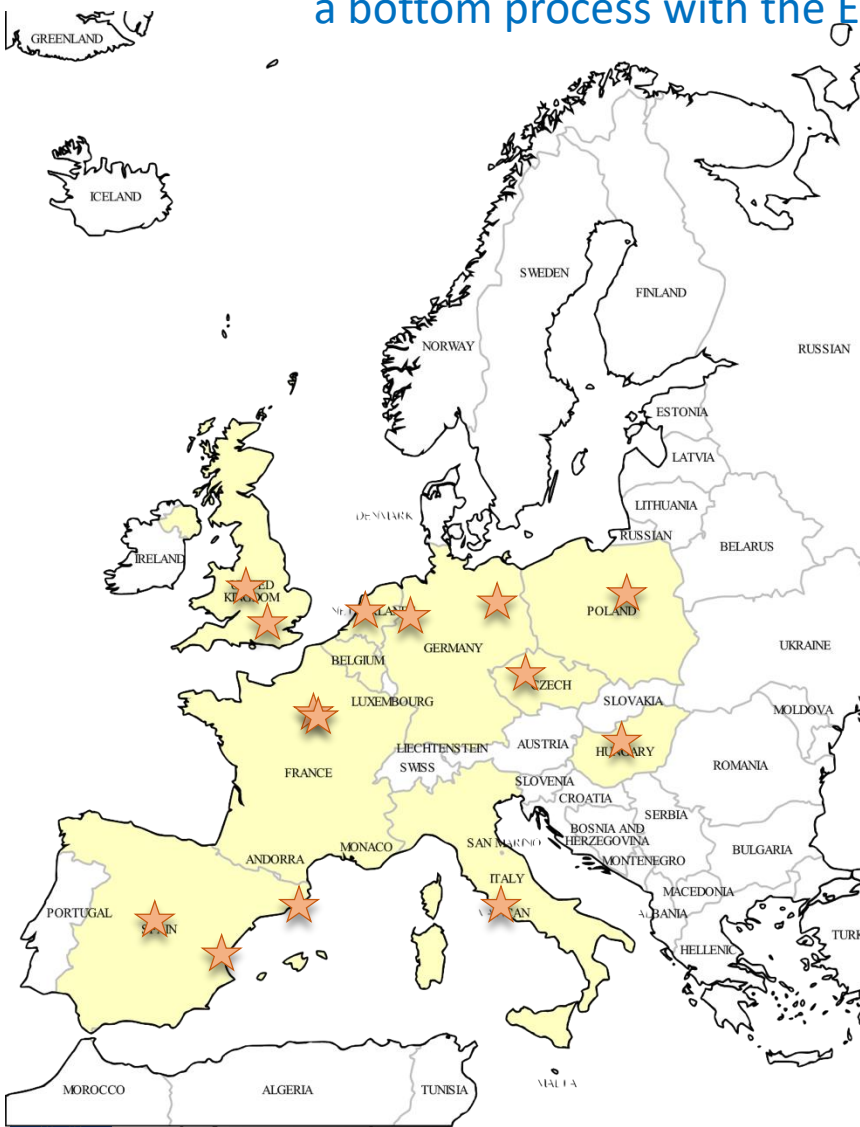
Hubs of Coordination holding high expertise  
for special interventions and advise -  
a bottom process with the European clinical trial committee



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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 Curie, Paris
4 <b>France</b>	Fondation Rothschild, Paris
5 <b>Germany</b>	Charité Universitätsmedizin Berlin (Charité)
6 <b>Germany</b>	University Clinic Essen
7 <b>Hungary</b>	Semmelweis University Budapest
8 <b>Italy</b>	Ospedale Pediatrico Bambino Gesù, Rome
9 <b>Netherlands</b>	VU University Medical Center, Amsterdam
10 <b>Poland</b>	Memorial Children's Hospital, Warsaw
11 <b>Spain</b>	Hospital universitario La Fé, Valencia
12 <b>Spain</b>	Hospital Universitario Vall d'Hebron
13 <b>Spain</b>	Hospital Sant Joan de Déu, Barcelona
14 <b>Spain</b>	Hospital Carlos III (Madrid), Madrid La Paz
15 <b>UK</b>	Birmingham Children's Hospital (UOB)
16 <b>UK</b>	Great Ormond Street Hospital, London



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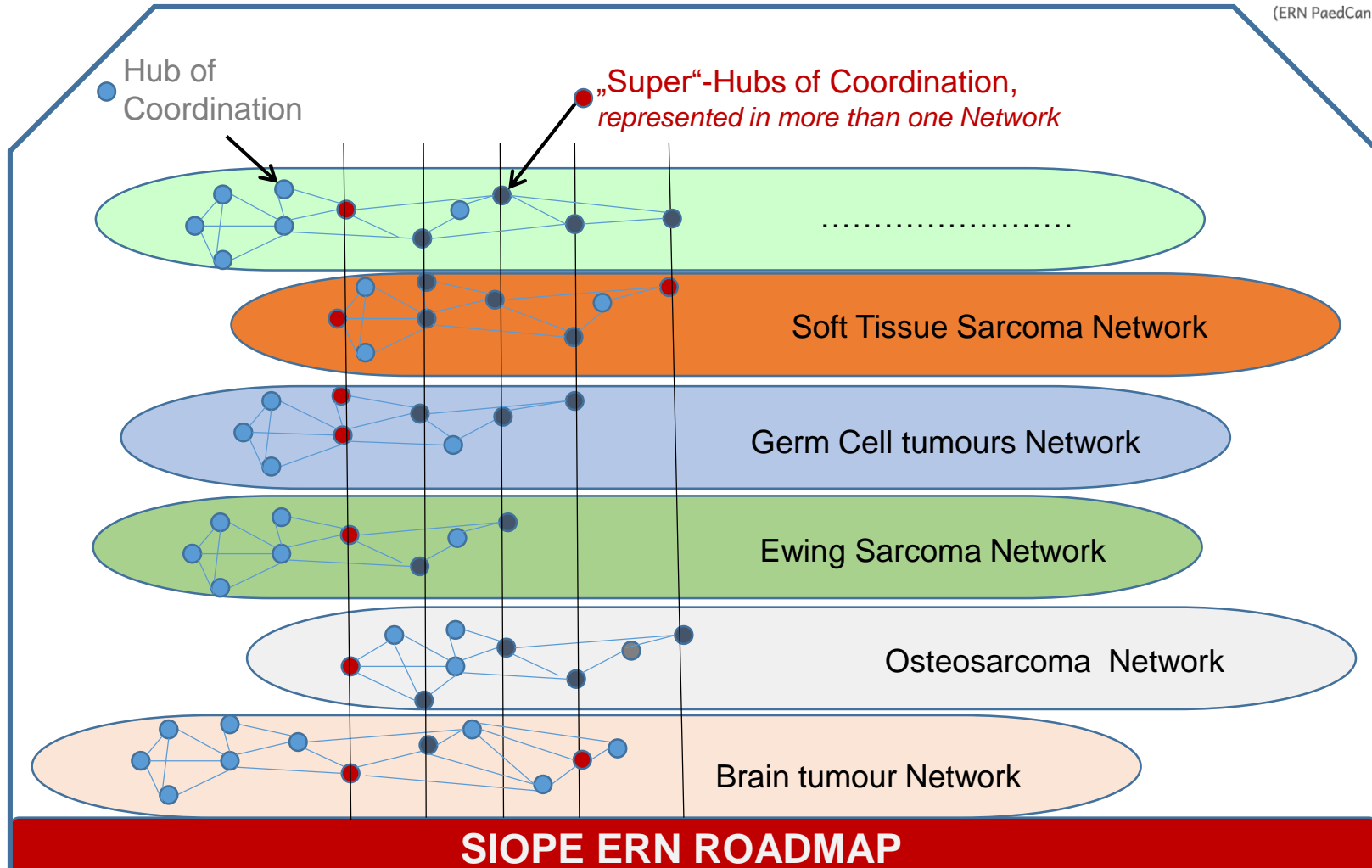
# Planned Roadmap Layers – Step by Step annual add-on Strategy



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# Innovation in Patient Pathways

## ■ ERN PaedCan Roadmap

- Helps to make Treatment Standards visible as embedded in the ECTG-SIOPE - ERN PaedCan Road Map
- Identifies respective critical interventions and situations where patients benefit from referral to centres with a high level of expertise (very specialised surgeries , proton therapy , ...)
- Support needed to increase the collaboration and compliance of MS
- **Survey on MS commitments on S2 application needed- does it work as planned ? Is it satisfactory for patients and HCPs in CBHC situations?**
- **CBHC arrangements currently ( S2 ) do not cover treatments in early development and hence prohibit access of patients to innovation**

 **Need to adopt current rules for S2 – Negotiation between MS needed!**







# Innovation in Patient Pathways

- **EU Clinical Patient Management System (CPMS)**
  - Information travels rather than the patients – concept is brilliant!
  - The system for free – excellent !
  - Modern and GDPR compliant consulting system
- **But**
  - Work intensive processes and major time investments of experts
  - No reimbursement scheme Europe for advisory functions within health care pathways!
  - Needs a good balance of HCP engaged – number of partners in ERN PaedCan to increase, but that needs support and management
- ☞ **Need for a smart compensation scheme between individual HCPs across borders for virtual advise**
- ☞ **CPMS needs to be secured as a sustainable European structure!**

# Innovation in Patient Pathways



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## ■ Standard for Follow Up Care for Childhood Cancer Survivors

- Secure continuity of life –long care as needed as 75% of childhood cancer survivors face at some stage in life late effects
- **Adequate Care Centres** holding broad expertise for person centred Long Term Follow-Up are a pre-requisite !

## **Need to encourage European Long Term Quality Care Models for Cancer Survivors across MS!**

## ■ Survivor Care Plans & Survivorship Passport

- **Secure life –long relevant treatment information** about treatment burden and late effects
- Capitalize on European eHealth developments

## **Support for the implementation across Europe ! Needs EU – MS resources & funding !**



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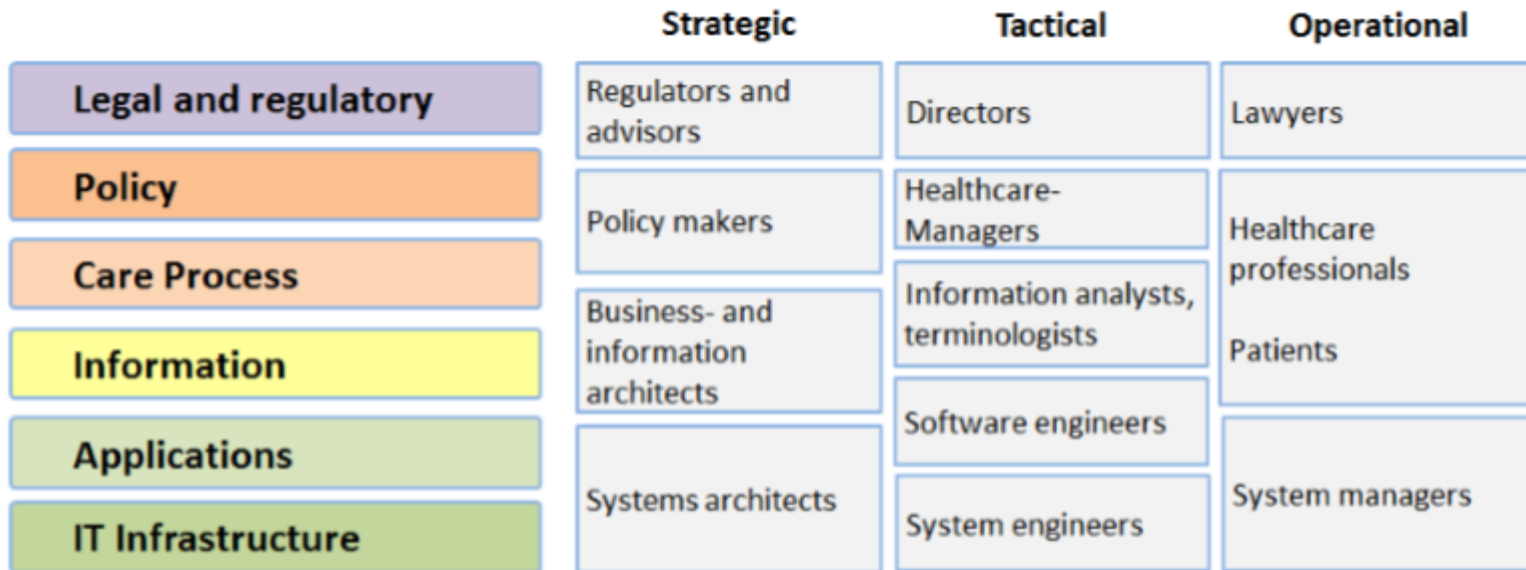


# eHealth in the European Union

## Methodology of the "Extended eHealth Interoperability Framework"

The 6 layer development plan

= A lot of home work to do!



Needed : An interdisciplinary group of leading experts covering the full spectrum, from technology, healthcare, governance, ethics, legal, economics, research and patients & survivors


# “Twinning Support”



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- Twinning of HCP across Europe for enhanced education, research and better quality in care & treatments
  - Aspects of Twinning - SIOPE perspectives
    - Support exchange of Health Care Personnel
    - Day to day Knowledge exchange using “Twinning” within the CPMS platform
    - Continued medical education WEBinars /CME points
    - 1 funded major educational event to embrace the whole community in need of upgrading knowledge of treatment standards
    - Enhancement of twinning by non- competitive initiatives to foster research & education across
-  **To overcome inequalities across Europe “Twinning” is key and requires non-competitive funding !**



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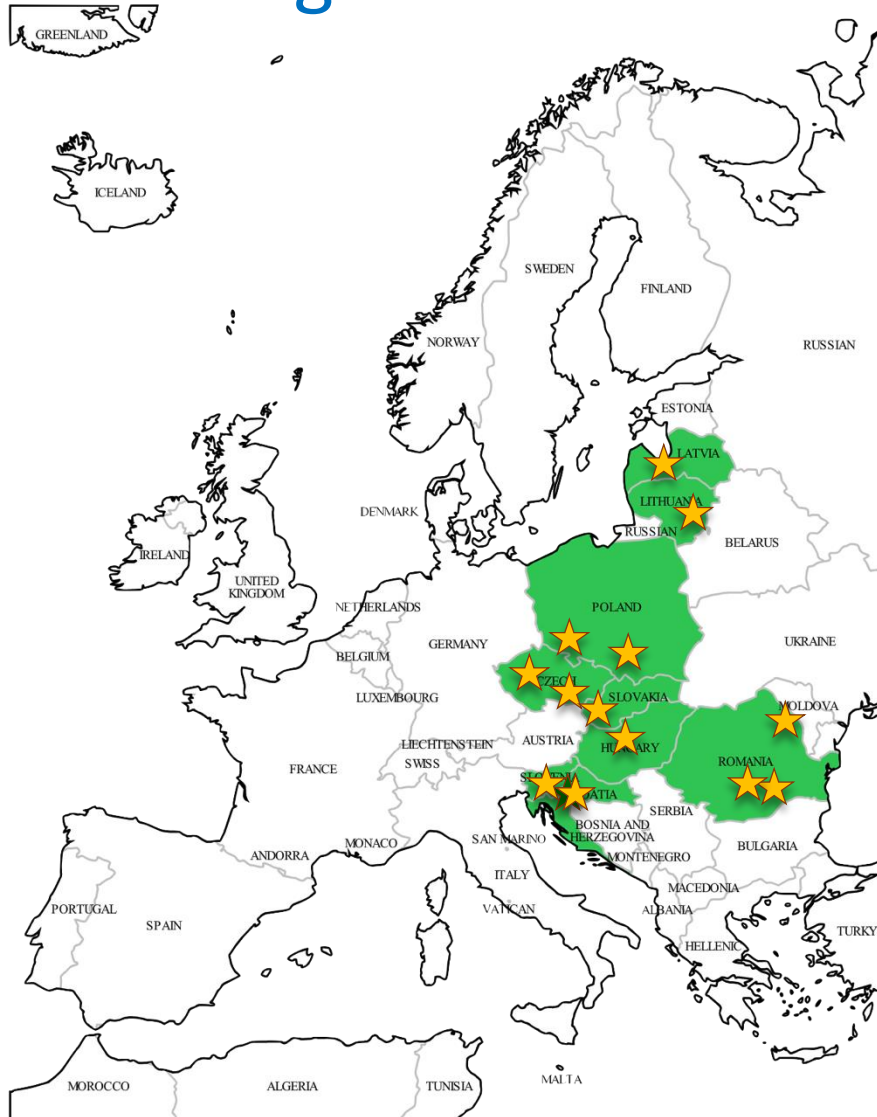
# LHEAR country HoCs: Targets of CBHC Cooperation



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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



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👉 **Need Europe to take responsibility on these aspects ! Need to intensify political efforts !**

👉 **Enhanced communication of EC & relevant ministry representation of MS-NHS to achieve enhanced MS commitment for the multiple actions to improve patient centric care models on the national level and CBHC commitments!**



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# Towards a brighter future for our children with cancer

## THANK YOU!



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