



10th Edition

International Childhood Cancer Awareness Day (ICCD2020)

18 February 2020
13:00 to 15:00

European Parliament
Brussels, Belgium



The European Reference Network Model and the great Potential of eHealth

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For a Brighter Future for Children & Adolescents with Cancer



18 February 2020

International Childhood Cancer Awareness Day 2020

www.siope.eu



ERN PaedCan: Vision & Mission



- **Equal and possible best paediatric cancer care and outcomes no matter where in Europe children live!**
 - All of Europe eHealth ready – A digital safe Health Space!
 - **Childhood Cancer Survivor Passport** as interoperable electronic Health Record including Patient Reported Outcomes (PROs) and long term surveillance
 - **Artificial Intelligence** as a game changer to gain new insights in paediatric cancer genesis , development allowing better treatments and better cures!
 - ERN PaedCan contributing to the European Beating Cancer Plan: **Understand - Prevent – Better Cures – Improved quality of live**



2019: 12 affiliated partners in widening countries adopted
 2020: Another 30 under evaluation for full partner ship

FULL MEMBERS AND AFFILIATED PARTNERS

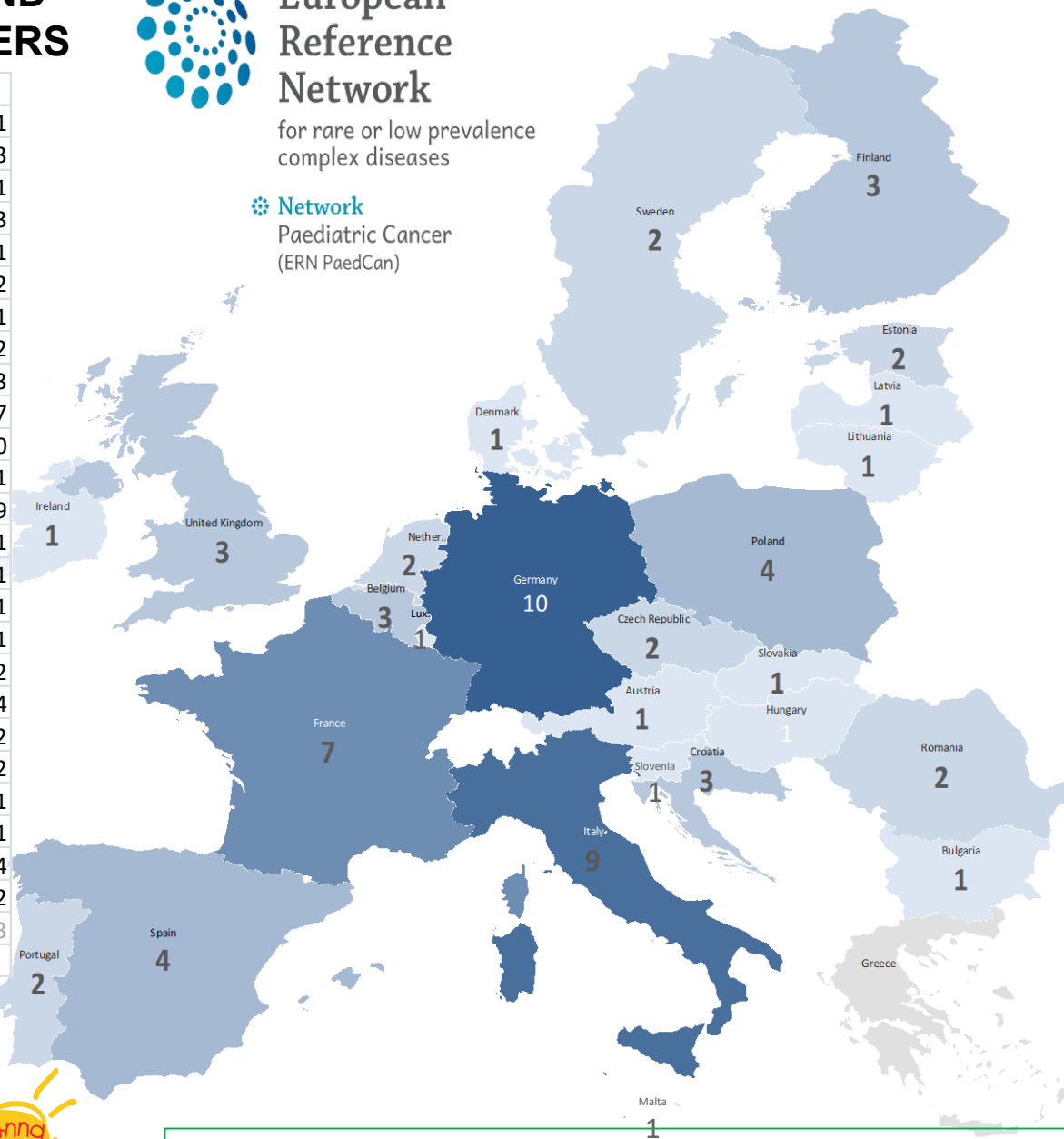


European Reference Network

for rare or low prevalence complex diseases

 **Network**
 Paediatric Cancer
 (ERN PaedCan)

Countries	FMs+Aps
1 Austria	1
2 Belgium	3
3 Bulgaria	1
4 Croatia	3
5 Cyprus	1
6 Czech Republic	2
7 Denmark	1
8 Estonia	2
9 Finland	3
10 France	7
11 Germany	10
12 Hungary	1
13 Italy	9
14 Latvia	1
15 Lithuania	1
16 Luxembourg	1
17 Malta	1
18 Netherlands	2
19 Poland	4
20 Portugal	2
21 Romania	2
22 Slovakia	1
23 Slovenia	1
24 Spain	4
25 Sweden	2
26 United Kingdom	3
Total:	69



Ireland and Greece applications for full membership



Cyprus
1



Diversity in Childhood Cancer Entities

The Strength of Collaboration & Shared Knowledge

16 European SIOPE Clinical Trial Groups
3 Overarching Organisations



> With molecular diagnostics sub-entities > 100





The Equity Challenge: 20% Inferior Paediatric Cancer Outcomes related to Low Health Expenditure Rates in Europe!

EU-member states with a per capita health expenditure in PPP <3.000 USD

- **>2000 U\$:** Cyprus, Czech Rep., Greece, Portugal, Slovakia, Slovenia
- **Between 1500 – 2000 U\$:** Croatia, Estonia, Hungary, Lithuania, Poland
- **Between 1000-1500 U\$:** Bulgaria, Latvia, Romania





European eHealth Readiness fundamental for improved interoperable Health Care and Research

- **Early and accurate rapid diagnosis with modern diagnostic tools**
 - ERN PaedCan – SIOPE networks to access best diagnostic procedures for correct risk estimates (modern molecular techniques & adequate staging of disease extent)
- **Right therapeutic choice**
 - Wrong early decisions impact survival chances and quality of cure !
 - SIOPE and ERN PaedCan launched the **European Standard Clinical Practice (ESCP)** Project to implement harmonized guidelines and treatment standards.
 - Need for an **ESCP Registry – Backbone for Outcome Research**





European eHealth Readiness fundamental for improved interoperable Health Care and Research

- **Implementation of Virtual Expert Tumour Boards**
 - Medical expertise and knowledge travels rather than patients !
 - Every child with cancer in Europe requires and deserves expert discussion in multidisciplinary childhood cancer tumour boards – locally or internationally !
 - Recognition of the **EU- Clinical Patient Management System (CPMS)** as an important eHealth- tool and source for Big Data
- **Cross-Border Healthcare at its best**
 - Unites the best experts across Europe to tackle complex Paediatric Cancer Conditions that require highly specialized interventions and a concentration of knowledge and resources
- **BIG DATA opportunities - overcome research data silos**
 - Collaborative Work with the ECTG and associated research groups
 - Integration of long term follow up data and patient reported outcomes
 - Integration of life style data,





An eHealth Use Case:

The Childhood Cancer Survivor Passport (SurPass) - as “Interoperable electronic Health Record”

- Today long-term survivors of childhood cancer face life –long challenges related to late effects (up to 60%) from the preceding, intense treatments based on old fashioned anti-cancer drugs.

- SurPass consist of a
 - Harmonized End of Treatment Summary (CDA- Doc)
 - Connects information with published late effects related to treatment burden
 - Gives Follow Up recommendation based on expectedness of late effects
 - Supports creation of personalized Long-term Care Plans
 - May nourish a long term follow up late effect surveillance registry data base

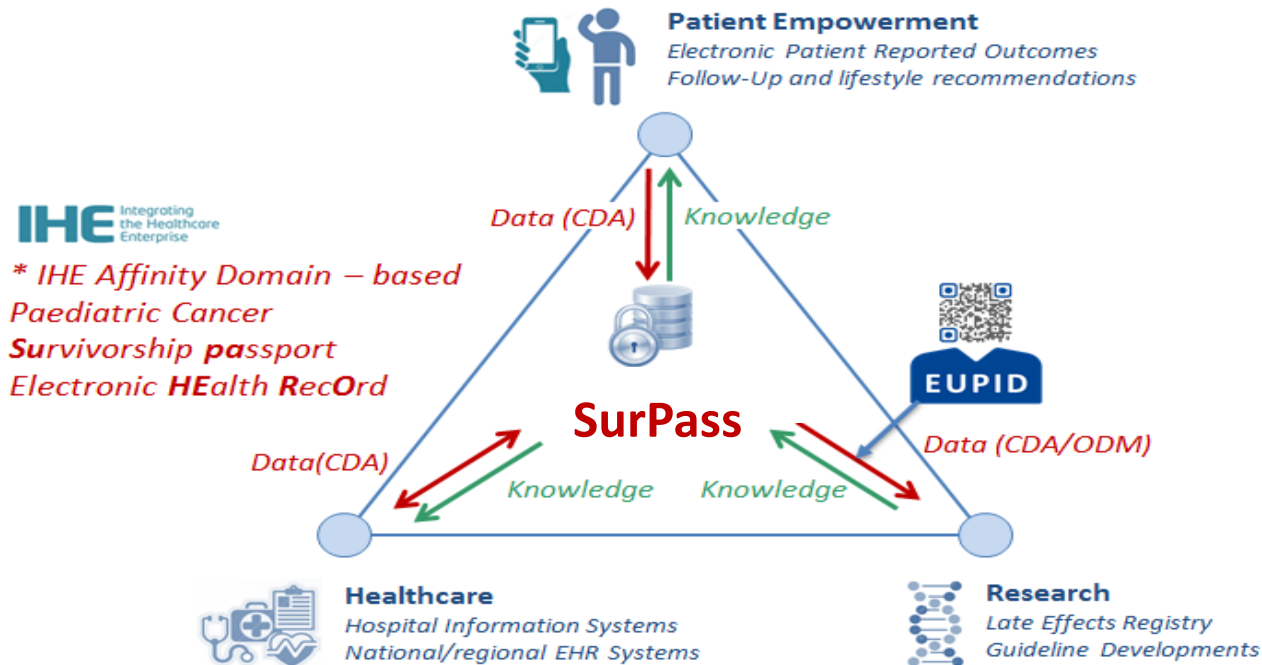
- ERN PaedCan may facilitate the implementation in respective national environments with flexible solutions depending on their **eHealth readiness**.





Interoperability is Key

- **Electronic Health Records and specific applications may facilitate lifelong collection and usage of health information and electronic Patient Reported Outcomes (ePRO)**
 - to increase our understanding of the cause, context and impact of late effects
 - to help to improved future paediatric cancer treatments and care





What is needed ?

6 -level Approach Proposal by the eHealth Network to achieve Interoperability in Healthcare

	Strategic	Tactical	Operational
Legal and regulatory	Regulators and advisors	Directors	Lawyers
Policy	Policy makers	Healthcare- Managers	Healthcare professionals
Care Process	Business- and information architects	Information analysts, terminologists	
Information		Software engineers	Patients
Applications	Systems architects	System engineers	System managers
IT Infrastructure			

A true European Challenge !

The European Cancer Plan is an implementation opportunity!





ERN PaedCan is a real European Opportunity for the Paediatric Cancer Community if correctly funded !

- Europe may capitalize on previous investments by fostering further this network developed in cooperation between EC and MS with a common vision and mission!

Marti-Bonmati

- Connects Paediatric Comprehensive Cancer Health Care Centres and Research Clusters
- Opportunities for Big Data and AI based on seamless cross-talking eHealth structures





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Carina Schneider, MSc

*Childhood Cancer International – Europe
Austrian Childhood Cancer Organisation*

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80 % of childhood cancer survivors survive – and then?

- 80 % childhood cancer survivors survive
- 300.000 – 500.000 survivors in Europe
- 2/3 suffer from moderate to severe late-effects
 - Physical, psychological and social
- Lack of adequate, comprehensive follow-up structures
 - lack of awareness about late-effects
 - lack of guidance reg. follow-up care

⇒ need for Survivorship-Passport, follow-up clinics and research on survivorship!





Survivorship-Passport – Big data after cancer

- Web-based and printable document
 - Information about cancer and its treatment
 - End-of-treatment summary
 - Individual late-effects-risk
 - Follow-up recommendations
- What are the opportunities?
 - Boosting **research** in long-term outcomes by cross-border ehealth exchange
 - Improving follow-up recommendations
 - **Improving treatment => reducing late-effects**

We are willing to share our data – for the sake of better survival, also for future survivors!

- Why is it so important for childhood cancer survivors?
 - Full disclosure
 - Health management – empowerment
 - Prevention
 - Easy access, everywhere





Good news from Austria

Coming up: Implementation in Austrian eHealth-record ELGA

- Included in national cancer plan
- Implementation planned in multi-stakeholder collaboration
 - Ministry of health
 - Academia
 - eHealth experts
 - Patient Advocates
- **4.2.2020:** Implementation in ELGA confirmed by health minister during press conference on world cancer day





For the rest of Europe?...

We are impatient!

- Survivorship-Passport has been ready since 2016
- Where is it implemented in 2020?
 - Italy
- Why?
 - Finances
 - Cross border data-transfer
 - Lack of structures for follow-up care incl.
 - Lack of interoperability
 - Lack of uniform eHealth record format





Raise your hands for survivors!

500.000 survivors in Europe need **YOUR** support – and the support of their health care systems!

Sign our petition for better follow-up care structures across Europe.





#RaiseYourHands4Survivors

Thank you.

Get in touch: europe@cci.care

