



European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment

ExPO-r-Net



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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 even larger for paediatric cancers with poor outcomes



ExPO-r-Net Goals

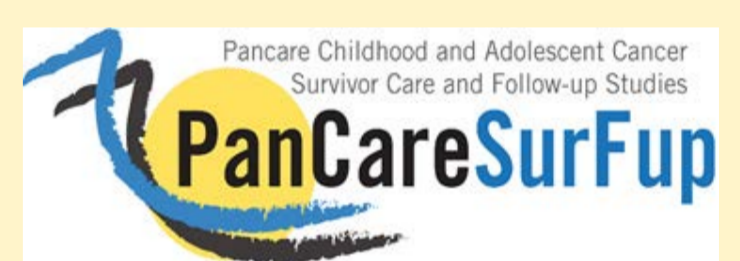
- **Link** paediatric oncology centres of excellence
- **Enable treatment** of young people with cancer in other EU Member States
- **Improve access** to high-quality health-care for all young people with cancer
- **Reduce inequalities** in childhood cancer survival and healthcare capabilities across the EU
- **Empower patients** affected by complex or rare diseases to choose and be reimbursed by public and private health care providers across the EU

...because European Children & Adolescents with Cancer deserve the best possible Treatment - no matter where they live!

Quality of Partnership

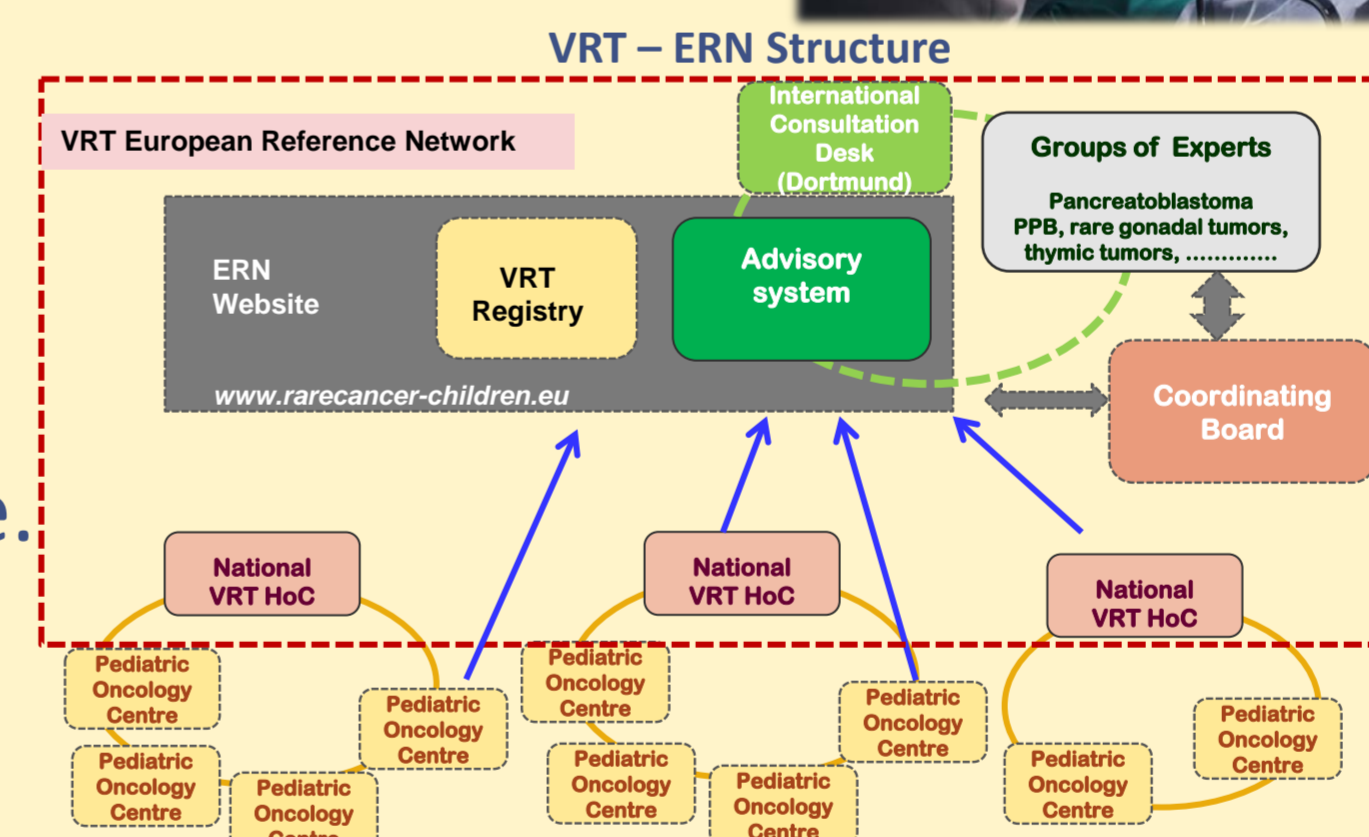
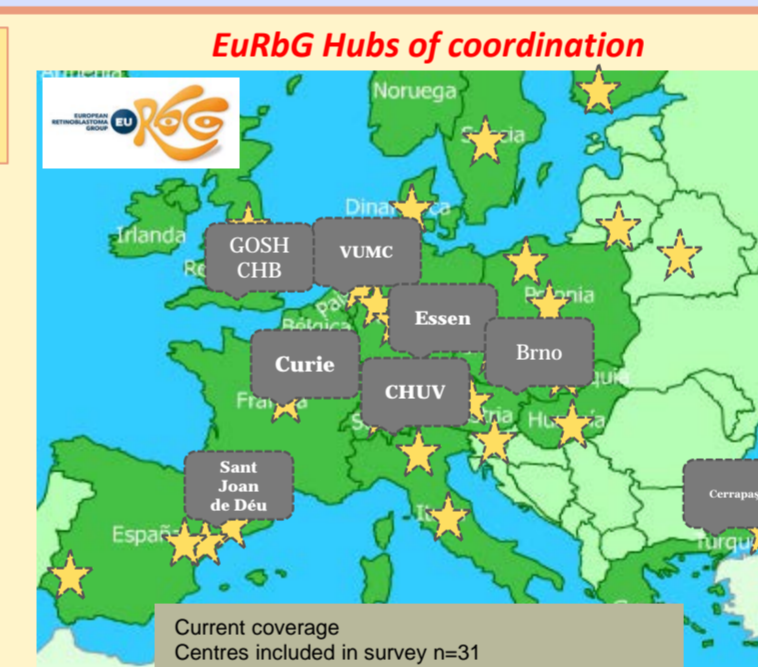


- **European Society for Paediatric Oncology (SIOPE)**
- **Integration**
 - European Clinical Research Council (SIOPE - CRC) for paediatric oncology (NAPHOS / ECTG)
 - Childhood Cancer International (CCI) - Integration of parents and patients groups
 - Pan-European Network for Care of Survivors after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



Key concepts and Deliverables

- **Centre of excellence:** providing highly specialized healthcare.
- **Paediatric oncology reference roadmap:** containing approved expert referral sites & tumour advisory boards.
- **Identifying the special needs** of childhood and young people cancer types with experts (CRC).
- **ICT tools and e-Health:** to facilitate movement of information and knowledge rather than patients, whenever possible, keeping the patient within the supportive family and language environment.
- **Survivorship Passport:** already envisaged as part of several previous or ongoing projects, this instrument will be developed further for long-term follow-up of childhood cancer survivors across Europe.
- **Integrating very rare tumors (VRT)** and soft tissue sarcomas into an European reference network.



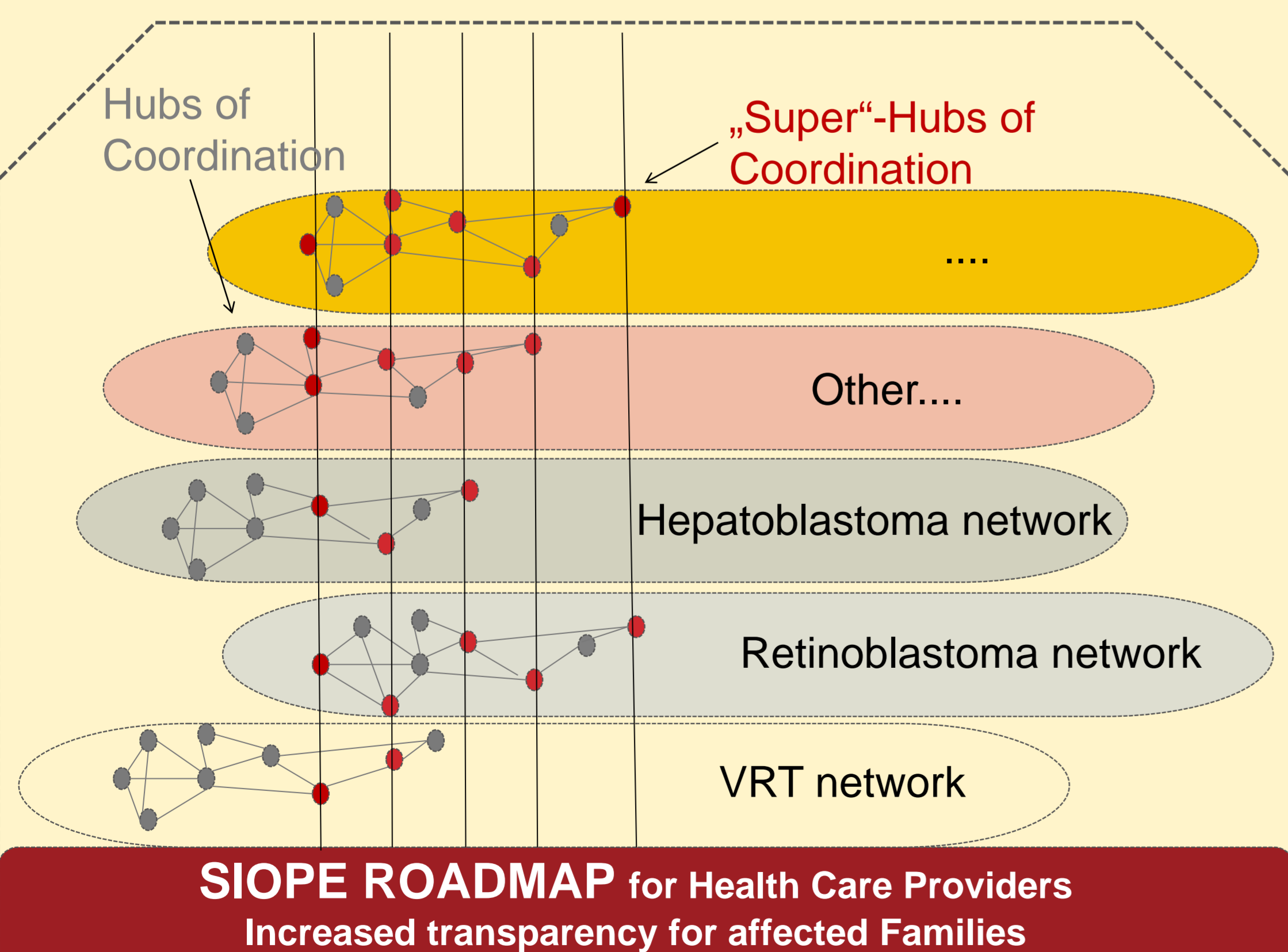
Stakeholders

- **More than 60 Partners from 17 countries**
- 18 Associated Partners from 9 EU countries
- More than 50 collaborating partners
- Involving patients and parents
- 8 Work Packages

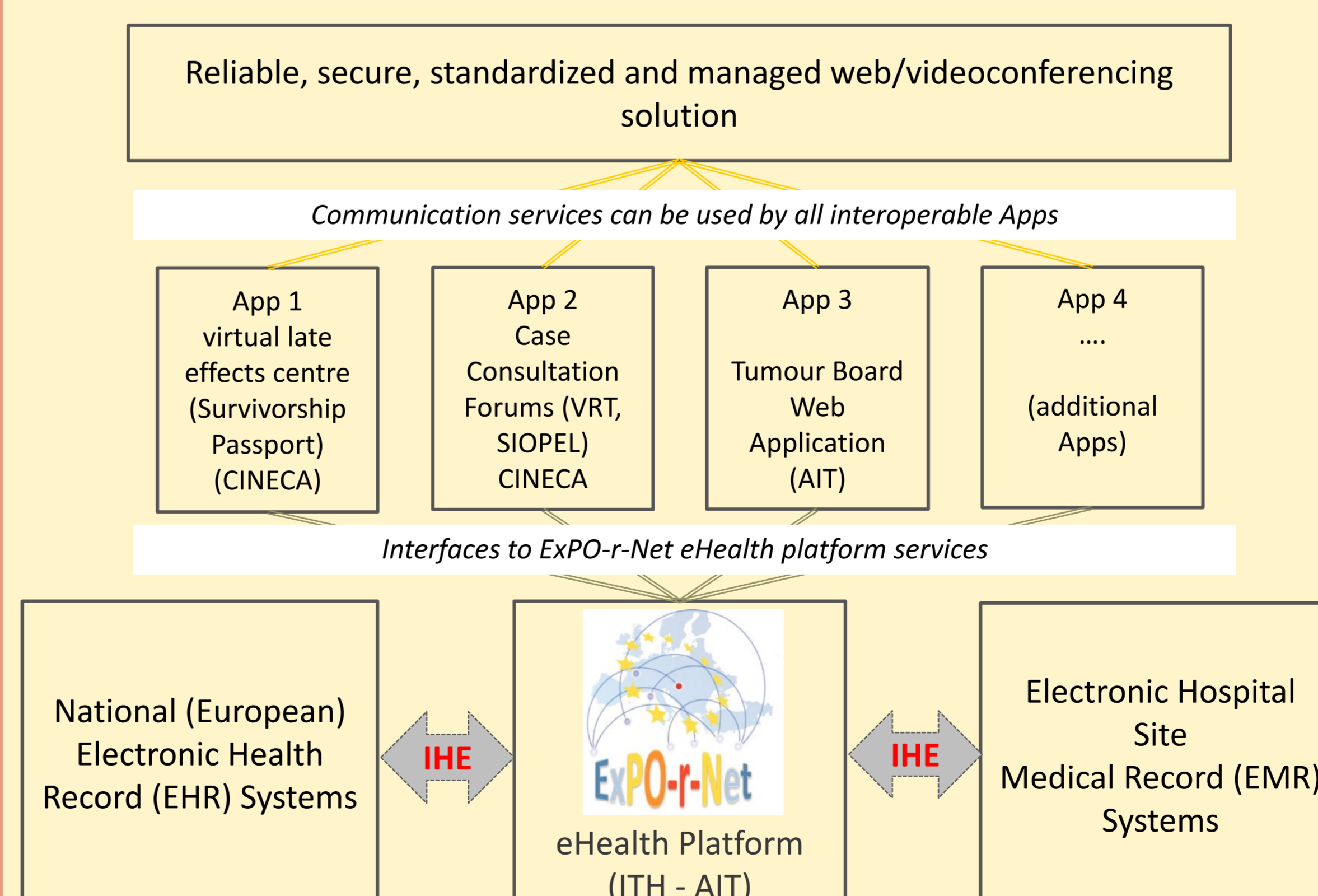


ExPO-r-Net Paediatric Oncology European Reference network

ExPO-r-Net PO-ERN



ExPO-r-Net eHealth Interoperability Architecture



Expected Impact

- **The strategic relevance**
- Provision of a framework for the PO-ERN to improve standards of care and outcomes for children with cancer.
- Incorporate expertise across Europe and collate existing information for patients to get access to best possible information, treatment and care.
- **The innovative contribution**
- A clear roadmap to approved expert referral sites and tumour advisory boards for healthcare providers.
- Fostering eHealth solutions based on interoperability and standardisation beyond borders.

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