

# ePTRI

EUROPEAN PAEDIATRIC TRANSLATIONAL RESEARCH INFRASTRUCTURE

# ID-EPTRI OPEN Meeting

April 3<sup>rd</sup> 2020



This project has received funding from the European Union's Horizon 2020 research and innovation programme under Grant Agreement No 777554

# ELSI Services

## Objective of the Common Service

- To protect the rights and well-being of children considered as “future generation”
- To promote appropriate research participation of minors based on age and mental capability
- To support the design of research studies in collaboration with research participants, particularly minors and their families
- To enter into and enable a dialogue, between policy makers, researchers, sponsors, patient organisations, families and minors
- To promote best practices, shared decision-making, science communication and participants empowerment
- To set up training and education on ELSI issues related to paediatric



## ELSI SERVICES & RESEARCH



### RESEARCH

Conducting research relating to ethical, legal and societal issues (ELSI) is fundamental to staying up to date with and contributing knowledge to current practices in both the biomedical scientific and regulatory field. This is core to the ELSI services we provide.

- [EU Projects](#)
- [Publications and Results](#)



### SERVICES

ELSI is key to any biomedical activity. We support the biobanking and life science RI communities by facilitating compliance with regulatory requirements and best practice standards.

- [ELSI Helpdesk](#)
- [ELSI Knowledge Base](#)
- [Ethics Check](#)
- [ELSI-Related Public Consultations](#)
- [Task Force Societal Issues](#)



### TRAINING

We provide ELSI training and workshops to researchers on ELSI issues such as Data Protection Impact Assessment (DPIA), ethical compliance and social engagement, among others.

- [ELSI Webinars](#)
- [ELSI Training Courses](#)

# Conclusion: collaborate

- An ELSI service for paediatrics needs to cover the unmet paediatric ethical needs relevant for the biobank sector including the use of cells and tissue samples related to paediatric patients (as donors and as recipients).
- It would also allow to reduce running costs of the service and ensure that during peak-times a service can be provided. Any tool and expertise proposed and established as a common service needs furthermore to be accurate and sustainable.
- It responds to the paradigm that tools developed in the context of research projects need to be maintainable by the core activities of the service and should not duplicate already existing services such as provided by other RIs or organisations.
- In conclusion, we recommend to implement the collaboration with existing services (such as the BBMRI-ERIC's) and tools (such as ECRIN's Campus tool), which are to be specified in collaboration agreements and guarantees sustainability, including not only tasks and responsibilities but also upfront clarification of any potential liabilities upfront, competencies, governance and organisation.

