



## **BBMRI** Initiative

"Pediatric Biobanking, Rare Diseases and Engagement -Join and Share Practices"

6 Sep 2021

BBMRI-ERIC and the Stakeholder Forum\* Patient Pillar are calling on pediatric & RD communities to engage in a network tackling pediatric biobanking and its ethical, legal, and societal challenges. This initiative is inclusive of all the actors involved in translational research and biobanking in addition to patients and biobankers, researchers, clinicians, ELSI experts, minor participants, citizen groups, etc.

### What are our goals?

To initiate a community of exchanging best engagement practices in pediatric biobanking;
To gain an overview of the established practices and/or expectations of various actors to improve empowerment and engagement processes.

Details:

Why do we pursue these goals?

why do we pursue these goals? Biobanking with minors/children is essential for providing tailored diagnostic and therapeutic answers as well as for identifying potential participants for a clinical trial in a vulnerable population. Children/minors are challenging as research participants who progressively acquire decision-making competence and legal capacity; therefore, the biobanking community needs appropriate empowerment & engagement models for the minor participant.

# Join & share your practices on pediatric biobanking https://forms.office.com/r/tnu4vWvW38

Replies welcome until 30th September 2021.

By signing up, interested parties will receive all the information to stay up to date and able to join future engagement activities.

(Just want to stay updated? Leave us your contact information on the first page of the form and skip

If you have any questions or comments, please contact <a href="mailto:sara.casati@bbmri-eric.eu">sara.casati@bbmri-eric.eu</a>

\*https://www.bbmri-eric.eu/stakeholder-forum/



## PEDIATRIC BIOBANKING AND ENGAGEMENT: JOIN AND SHARE PRACTICES



Replies welcome until 30th September 2021.

The initiative is co-funded within the CY-Biobank, a project that receives funding from the Euro Horizon 2020 research and innovation programme under grant agreement No 857122.

