



EUROPE BIOBANK WEEK 2022 ROADSHOW

An interactive Workshop

PAEDIATRIC BIOBANKING AND MINOR ENGAGEMENT

PRELIMINARY WORKING PROGRAM

DATE: 13th-14th October 2022

PLACE: Auditorium San Paolo, IRCCS Children's Hospital Bambino Gesù, Roma

Paediatric (research) biobanking is a European priority asking for an Ethical-Legal-Societal-ELS shift within a Responsible Research & Innovation - RRI framework. The EBW Roadshow aims to co-build a participatory and inclusive community of practices that tackles the challenges of biobanking with minors and their engagement. It sets up on the findings of the BBMRI ERIC 2021 open call "JOIN & SHARE YOUR PRACTICES ON PEDIATRIC BIOBANKING".

The workshop starts with an overall view of European commitment to paediatric research and healthcare and shares the BBMRI open call results, feedback from eighty-two respondents representing 22 countries. Respondents included biobankers and researchers, representatives from Patient Umbrella Organizations, industrial companies, and International Organizations. In this workshop several of these pioneers will help to stimulate exchange on established good practices and priorities of various actors to improve empowerment and engagement in paediatric (research) biobanking. These good practice examples will inspire in-depth exchanges to set out how we can comply with the EU's Horizon Europe goal to implement Responsible Research and Innovation and its commitment to open science with and for young researchers and citizens. This workshop aims to deepen community engagement among stakeholders from the pediatric and RD community, to share and promote practical solutions, and to address ELS challenges, which we aim to foster at the ELSI Knowledge Base.

SPECIFIC OBJECTIVES:

- To identify and share good practice examples to inform, involve and engage the minor as a participant
- To pinpoint common practical challenges and expectations across our extended, participatory biobanking community, and to share ideas and solutions for overcoming or addressing them
- To provide renewed focus for National Nodes and inspire new opportunities for new generations and new methods of citizen engagement in sample/data-based research
- To identify the most practical and efficient ways to connect and to improve both an extended community of practices and our ELSI knowledge base as a common good
- To prepare for the next EU calls focused on pediatric research and healthcare

FIRST HALF-DAY SESSION (Thursday afternoon) – 12:45 – 18:00
Success stories session 18:00 – 19:00

11.30- 12:45

Registration and light lunch (TBC)



12:45 - 13:00

Welcome & opening

BBMRI ERIC, ESBB and host representatives

13:00 – 14:30 - Overview session

A COMMON RESPONSIBLE HORIZON TO FOSTER PAEDIATRIC RESEARCH AND HEALTHCARE

A European priority: paediatric research and healthcare.

Industry as a partner to respond to the paediatric challenge

Paediatric biobanking in the European Reference Networks.

The role of paediatric biobanking in translational medicine. A showcase from the IDEA network: system-medicine in microbiome - diagnostic & therapeutic approach

14:15 - 14:30

Q&A

POOLING GOOD PRACTICES, TACKLING CHALLENGES FOR BIOBANKING WITH MINORS

14:15 –14:30

Sharing the results from Paediatric biobanking and engagement call for participation.

Introduction to the proactive good practice sessions (collecting comments, questions, other best practices in real time; launching pools on the key issues)

14.30 - 15:15 -1st good practice session

BIOBANKING, RESEARCH CONCERN ME – RAISING AWARENESS AND CITIZEN SCIENCE

Biobanking in the modern world involves data and sample-based research. It presupposes the construction of an inclusive extended scientific community to work as a team between all the players. It asks for a new social pact for science. Without citizens' understanding and engagement, biobanking does not work. Patients, citizens, and families, new generations, are the heart of biobanking making it possible.

15:15 - 15.45 Break and sponsor exhibition

15:45 - 16:30 – 2nd good practice session

FROM ASSENT TO CONSENT (AT THE LEGAL AGE): COMMON ISSUES AND DIFFERENT APPROACHES

Biobanking with children challenges our practice. It requires us to recognize the child as an active participant, with all the rights that we confer on adults. We need to rethink the issues of assent and consent, and to move towards dynamic and participatory models of regulation and interpretation. It's a huge change of pace and represents a significant challenge in terms of engagement of a participant, the minor, who progressively but often separately acquires decision-making competence and legal capacity. So, who is primarily responsible for proposing to the minor that he or she might participate in research biobanking? What tools are available to inform and increase the child's understanding? By whom is the child's capacity to understand and to assent assessed?

16:30 – 17:15 – 3rd good practice session

MULTI-ACTOR ENGAGEMENT TO BIOBANK TOGETHER (EARLIER, OVER TIME, FOLLOWING UP)



Biobanking can be compared to a team-game, to the multidimensional action of a system based on transparency, inclusion, participation, and reciprocal engagement. Each actor, from the family to the clinicians, to the Research Ethics Committees, the researchers, etc., in a reciprocal way, is necessary for the development, sustainability, and fairness both of biobanking and data-based science. This is critical with children, they are individuals in evolution, with a situated vulnerability in transition: paediatric (research) biobanking practices need to collect samples before disease develop and maintain a prospective follow-up. Such a process would entail the involvement and the aware commitment of all the players along time. This implies a training shift based on innovative empowerment models and engaging all the actors.

17.15 – 17:30

First day insights in view of the co-designed statement

17:30 - 18:00 * potential sponsor slot**

18:00 – 19:00

Success stories session - PAEDIATRIC BIOBANKING AND INNOVATION IN CHILDREN

From innovative genomic approaches with undiagnosed patients to paediatric precision medicine

From 19:00: networking evening

2ND HALF-DAY SESSION (Friday morning) – 09:00 – 12:45

9.00 – 9:15

Work Summary and Introduction to Day 2 - Interactive Training for a Community of Practice.

Two sessions where small groups will work in parallel to recognise and map good practice, training and learning from each other to build a paediatric (research) biobanking community based on shared knowledge and strengthened skills. Each group will be facilitated by speakers and chairs from day one, of the good practice sessions.

9:15 – 10:15 – Interactive Training for a Community of Practice – Part 1

BIOBANKING TOGETHER: RAISING AWARENESS AND DELIVERING CITIZEN SCIENCE WITH NEW GENERATIONS OF CITIZENS AND RESEARCHERS

10:15-10:30

Sharing outputs

10:30 – 11:30 – Interactive Training for a Community of Practice – Part 2

MINOR ASSENT AND PARTICIPATION IN RESEARCH AS A MULTI-ACTOR DYNAMIC PROCESS

11.30 – 12.00 Break and sponsor exhibition

12:00 – 12:30

Shared statement and next steps

12.30 - 12.45

Take home message!