

EUROPE BIOBANK WEEK 2022

ROADSHOW

ESBB

European Pediatric
Biobanking & Research Society
for Organizational
and Biobanking



BBMRI-ERIC

PEDIATRIC BIOBANKING AND MINOR ENGAGEMENT
AN INTERACTIVE WORKSHOP
13-14 OCTOBER, ROME, ITALY

PRELIMINARY

SCIENTIFIC PROGRAMME



EUROPE BIOBANK WEEK 2022 ROADSHOW

An interactive Workshop

PEDIATRIC BIOBANKING AND MINOR ENGAGEMENT

DATE: 13th-14th October 2022

VENUE: Auditorium San Paolo, Ospedale Pediatrico 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. Therefore, the EBW Roadshow aims to co-building 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 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 sharing the BBMRI open call results, which stems from the feedback from eighty-two respondents representing 22 countries joined. Among the respondents were plenty of biobankers and researchers, alongside some critical representatives from Patient Umbrella Organizations, companies, and International Organizations. In organizing this workshop, we invite several of these pioneers to present to stimulate exchange on established practices and priorities of various actors to improve empowerment and engagement. This will allow an in-depth exchange and propose how to comply with the EC’s Horizon Europe goal to implement both Responsible Research and Innovation and open science with the young generation of researchers and citizens. Ultimately, this workshop aims to deepen community engagement among stakeholders from the pediatric and RD community, promoting practical solutions, and addressing ELS challenges, which we aim to foster at the ELSI Knowledge Base.

Venue Address:

Viale Ferdinando Baldelli 38
Roma
Basilica San Paolo



FIRST HALF-DAY SESSION (Thursday afternoon) – 12:45 – 17:45
Networking session 17:45 – 18:45

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.

IDEA Network and the paediatric translational medicine.

System-medicine in microbiome. Diagnostic & therapeutic approach

14:15 - 14:30

Q&A



POOLING TOGETHER 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 exchange sessions (collecting comments, questions, other best practices in real time; launching pools on the key issues)

14.30 - 15:15 -1st session

Biobanking, and data and sample-based research, presuppose 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. Biobanking needs scientific citizens not just to be supported and legitimated but to exist de facto: patients, citizens, and families, new generations, are the heart of biobanking making it possible.

15:15 - 15.45 Break

15:45 - 16:30 - 2^o session

FROM ASSENT TO CONSENT (ATTAINING AT THE LEGAL AGE): DIFFERENT APPROACHES, COMMON ISSUES & PLAYERS

Biobanking with children challenges our practice, requiring us to recognize the child as a participant in his or her own right, with all the rights that we confer on adults. This implies to deeply rethink the issues of assent and consent, moving toward 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 acquires decision-making competence and legal capacity. Moreover, growing and acquiring capabilities, minors highlight the direct link between consenting attaining the legal age, follow-up, and engagement that is critical for sustainable, fair biobanking. Thus, in practice: who is primarily responsible for proposing to the minor to participate in research biobanking? Which tools to inform and increase minor's understanding? By whom is the child's capacity (to understand, to assent) assessed?



16:45 – 17:30 - 3^o 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.

17.30 – 17:45

First day insights in view of the final statement

17:45 – 18:45

Networking session - PAEDIATRIC BIOBANKING AND INNOVATION IN CHILDREN

Success stories: from innovative genomic approaches with undiagnosed patients to precision medicine

From 19:00: Networking evening



2ND HALF-DAY SESSION (Friday morning) – 09:00 – 12:45
Possible Satellite Event in the afternoon

9.00 – 9:15

Work summary and introduction to the breakout parallel sessions

Each parallel session will be facilitated by an ELSI expert/ESBB representative and a SF Patient Pillar representative and will have the same outline co-produced during the summer and integrated the day before as a common baseline.

9:15 – 10:15 - 1° breakout parallel sessions

BIOBANKING TOGETHER. RAISING AWARENESS AND CITIZEN SCIENCE WITH NEW GENERATIONS (BOTH CITIZEN AND RESEARCHERS): WHICH CROSS-CUTTING ACTIONS, WHICH EMPOWERMENT PATHS, WHICH TOOLS

10:15-10:30

Sharing outputs

10.30 – 11:30 - 2° breakout parallel sessions

MINOR ASSENT AND PARTICIPATION IN RESEARCH AS A MULTI-ACTOR DYNAMIC PROCESS. STRENGTHEN A PARTICIPATORY COMMUNITY OF PRACTICES. HOW TO CONNECT... HOW TO EXCHANGE ... HOW TO ENGAGE

11.30 – 12.00 Break

12:00 – 12:30

Shared statement and next steps

12.30 - 12.45

Take home message!



Suggested accommodations

ALONG THE METRO LINE B

Medium price accommodations

Ostiense Station/Trastevere Station (Airport Fiumicino Express stops here)

B& Easy:

€ 80 <https://bnbeasy.it/>

St. Paul Palace Relais:

€ 80-90 https://st-paul-palace-relais.business.site/?utm_source=gmb&utm_medium=referral

Lungotevere Suite:

€ 90-100 <http://lungoteveresuite.com/>

Hotel S. Prisca:

€ 90-100 <https://www.hotelsantaprisca.it/>

Colosseo District

RE Monti Guest House

€ 80-90 https://www.remontiroma.com/?utm_source=GB&utm_medium=organic



Termini District

Aelius

€ 90-100 <https://www.roma-inn.com/>

Hotel Aberdeen

€ 90-100 <https://www.hotelaberdeem.it/>

Hotel Parker

€ 90-100 <http://www.hotelparkerroma.it/>

Downtown, Piazza Spagna District (metro line A, change at Termini to Basilica San Paolo)

Hotel 3 stars (approximately 200-220 euro per night in a double room)

Hotel Scalinata di Spagna

<https://www.hotelscalinata.com/>

Hotel Manfredi Suite

<https://www.hotelmanfredi.com/en/boutique-hotel-via-margutta-roma>

Hotel Tritone

<https://www.tritonehotel.com/>

Hotel Accademia

<https://www.accademiahotel.com/it/hotel-fontana-di-trevi/>



Hotel San Silvestro

<https://www.hotelsansilvestroroma.com/index.php>

Hotel 4 stars (approximately 230-270 euro per night in a double room)

Hotel Mozart

<https://www.hotelmozart.com/en/>

Hotel Valadier

<https://www.hotelvaladier.com/en/>

Hotel Code

<https://www.thecodehotelrome.com/>

Hotel Stendhal

<http://www.stendhalhotelrome.com/index.htm>