



SYMPOSIUM

ETHICAL, LEGAL AND SOCIETAL INSIGHTS & OUTLOOK FOR BIOBANKS AND MEDICAL RESEARCH

Programme
V1.0

4-6 June 2024

Lyon, France

TUESDAY – 4 JUNE 2024

12:30 Registration

14:00 *Welcome & Setting the Scene*

Michaela Th. Mayrhofer (BBMRI-ERIC)

14:00 *SESSION 1: GENETICS AND GENOMICS*

Keynote: Ethical Concepts in Biobanking from a Middle-Income Perspective. The Experiences from Egypt
Amany Maher (MASRI)

The Concept of Genetic Privacy: Insights from Empirical Research in Cyprus
Georgia Charalambidou (CY-Biobank)

Empowering Change: The Role of the BBMRI National Node ELSI Working Group towards Modernising Biobanking Regulations in Hungary

Eszter Tuboly (Hungarian Pediatric Oncology Network), Regina Felső (Szentágotthai Research Centre) et al.

Research Fields and Data Modes of Emergence: Insights for Biobanking, Genomics and AI
Kaya Akyüz (BBMRI-ERIC/University of Vienna)

Panel Discussion

16:00 Coffee Break

16:30 *SESSION 2: "FROM GUT TO SPACE"*

Keynote: IARC's experiences with ethics over the last decade

Chiara Scoccianti (IARC/WHO)

Navigating New Waters: Implications and Challenges for Biobanks in the European Health Data Space
Isabel Huys (University of Leuven, Belgium) et al.

Ethical and Legal Implications of Research Microbiome Samples

Catarina Almeida (University of Vienna, Austria)

Polish Experience in Creating a Legal, Social and Ethical Framework for Biobanking

Dorota Krekora-Zajac (University of Warsaw, Poland)

Panel Discussion

18:30 End of Day 1

19:30 Reception

WEDNESDAY – 5 JUNE 2024

8:00 Registration

9:00 SESSION 3: "IT'S THE DATA, STUPID!"

Keynote: "All the Data from Everywhere all at Once": Visions and Practicalities in Data Integration

Klaus Høyer (University of Copenhagen)

International Data Sharing for Optimal Patient Care

Tom Southerington (University of Turku/FINBB)

MMCI's Biobank and Increasing Usage of Next-Generation Sequencing

Radek Halouzka, Jan Kuran (Masaryk University)

The Importance of Integrating an Inclusive Sex- and Gender-Sensitive Perspective in Data Driven Biomedical Research

Mónica Cano Abadía (BBMRI-ERIC)

Panel Discussion

11:00 Coffee Break

11:15 SESSION 4: "BACK TO THE FUTURE!"

Presentations by Young Researchers

Podium Discussion

Michaela Th. Mayrhofer (BBMRI-ERIC), Anne Cambon-Thomsen (University of Toulouse), Marialuisa Lavitrano (University Milano-Bicocca), Zisis Kozlakidis (IARC/WHO)

13:00 Lunch Break

14:00 SESSION 5: "REQUESTING AGENCY"

Keynote: The WHO Office of Bioethics: Projects and Priorities

Andreas Alois Reis (WHO)

MyGenome Portal: A Comprehensive Platform for Return of Results over 200,000 Estonian Biobank's Participants

Liis Leitsalu (University of Tartu) et al.

The Nagoya Protocol Applied to Swiss Biobanks

Joséphine Uldry (Swiss Biobanking Platform/EPFL) et al.

Panel Discussion

16:00 Coffee Break

16:30 SESSION 6: "ASSESS – ENABLE – TRUST"

Keynote: How Has Oncology Practice Changed Over the Pandemic?

Brenda Boegard (University of Lausanne) – *recording*

Managing Incidental Findings at Hospital-Based Biobanks

Roland Jahns (Universitätsklinikum Würzburg)

Constitution and Distribution of Organoids and Experimental Models. Legal Implications for Biobanks in Spain

Pilar Nicolás (University of the Basque Country)

Ethical Challenges in the Era of Medical AI: Biobanks Trustworthiness, and Societal Implications

Melanie Goisauf (BBMRI-ERIC)

18:30 Panel Discussion

THURSDAY – 6 JUNE 2024

8:00 Registration

9:00 SESSION 7: "AT LEAST, ASK!"

Biobanking with Children – Ethical, Legal and Social Issues in the Maltese Context

Gillian M Martin (University of Malta) et al

Implementing Broad Consent for Research with Routinely Collected Clinical Data and Residual Biosamples in a Cancer Hospital: Does this Lead to Underrepresented Groups in Research?

Miriam Beusink (Antoni van Leeuwenhoek Hospital) et al.

Strengthening a Biobanking Participatory Ecosystem, Cocreating a Biobank APP with a Digital Informed Consent/Assent Matrix Integrated in the Biobank BIMS

Sara Casati (CNR) et al.

Towards a More General Consent for the Use of Patient's Biological Material and Health Information for Medical Research – The Patient Perspective

Isabelle Budin-Ljøsne, Rebecca Bruu Carver (NIPH)

Panel Discussion

11:00 Coffee Break

11:30 SESSION 8: "NEW HORIZONS"

SciencE outreach: The example of BIObanks in Europe

Olga Tzortzatou-Nanopoulos (BRFAA)

Ethical, Legal, and Social Implications (ELSI) of Biobanking in Turkey

Yücel Erbilgin (University of Istanbul)

And Presentations by Young Researchers

13:00 Lunch Break

14:00 Closing: ...And Now to Something Completely Different!

Michaela Th. Mayrhofer (BBMRI-ERIC)

15:00 End of Meeting