



18 MAY 2023
BUDAPEST \ HUNGARY

WORKSHOP



FORENSIC DATABASES ADVISORY BOARD

PROGRAM

Program Topic:

Exploring the Role of Informed Consent, Ethical Considerations for Data Inclusion of Minorities and Vulnerable Groups, and other Key Factors for Comprehensive Risk-Benefit Assessment of Data Hosted on Forensic Genetic Frequency Databases.

09:00 AM - 10:00 AM

Presentation of the report by the FDAB

including Ethical Challenges
and Recommendations

10:00 AM - 10:15 AM

Short survey of participants

10:15 AM - 10:30 AM

Coffee Break

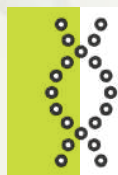
10:30 AM - 11:45 AM

Discussion on the following topics:

- Type of data and identifiability
- Identifying vulnerable populations
- Legacy data
- Data obtained without consent
- Key components of informed consent forms and information sheets
- Elements of informed consent for international data sharing

11:45 AM - 12:00 PM

Concluding Remarks



FDAB

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MEMBERS of the FDAB BOARD



Prof. Yann Joly, PhD (DCL), FCAHS, Ad.E. is the Research Director of the Centre of Genomics and Policy (CGP). He is a James McGill Professor at the Department of Human Genetics at McGill University. Prof. Joly is also an associate member of the Bioethics Unit and at the Law Faculty. He was named advocatus emeritus by the Quebec Bar in 2012 and Fellow of the Canadian Academy of Health Sciences in 2017. Prof. Joly is a member of the Canadian Commission for UNESCO (CCU). He is the current Chair of the Bioethics Workgroup of the International Human Epigenome Consortium (IHEC) and Co-Lead the Regulatory and Ethics Work Stream of the Global Alliance for Genomics and Health (GA4GH). He was Chair (2017–2019) of the Ethics and Governance Committee of the International Cancer Genome Consortium (ICGC). He is also a member of the Human Genome Organization (HUGO) Committee on Ethics, Law and Society (CELS). His research interests lie at the interface of the fields of scientific knowledge, health law (biotechnology and other emerging health technologies) and bioethics.



Prof. Maria Eugenia D'Amato is a Full Professor and Head of the Forensic DNA Laboratory at the University of the Western Cape, South Africa. Her research interests include forensic genetics, population genetics and genomics of African human populations, with a focus on understanding the processes contributing to observed patterns of variation. She has worked closely with local minorities and is interested in ethical issues related to her work. She led the development of a genotyping prototype with Y-chromosome markers tailored to African male diversity, earning her recognition as a runner-up for the Innovation Award of the National Science and Technology Forum of South Africa. She is also a founding member of the South African Academy of Forensic Sciences. MED received her biology degree from the National University of La Plata and her doctorate from the University of Buenos Aires, Argentina.



Dr Nathan Scudder is the Coordinator of Biometrics in the Forensic Command of the Australian Federal Police (AFP). He joined the AFP in 1999 and worked on various operations including the Bali Bombings and Indian Ocean tsunami of 2004. He was the first Forensic Coordinator in the major incident room for what later became Operation Arew., the AFP's response to the downing of Flight MH17. Nathan holds a Master's in Business Administration and Law, and a doctorate in biological sciences from the University of Canberra. He has led multiple teams in the AFP's Policing Development and Innovation area and Information Law, Policy, and Legislative Reform. Nathan is an Adjunct Associate Professor at the Centre for Forensic Science at the University of Technology Sydney and the Centre for Applied Psychology at the University of Canberra. Nathan continues to research and publish on advanced DNA technology.

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Dr Martin Zieger is an accomplished research group leader and forensic expert at the Institute of Forensic Medicine, University of Bern, Switzerland. He holds a PhD in Biochemistry, a MLaw, and the specialist title of "Forensic Geneticist" from the Swiss Society of Forensic Medicine. Martin's research activities cover a diverse range of topics, including population genetics, DNA sampling strategies, and DNA transfer and persistence. His particular interest lies in the legal regulation of Forensic Genetics. With his extensive knowledge and expertise, Martin has made significant contributions to the field of Forensic Medicine.



Prof. Helena Machado is a Full Professor of Sociology at the Institute for Social Sciences (ICS), University of Minho in Portugal. She is currently serving as the Chair of the Scientific Council for the Arts, Humanities, and Social Sciences for the Foundation for Science and Technology in Portugal. Helena has held several prestigious positions, including the Dean of the Institute for Social Sciences and the President of the Scientific Council of the Center for Social Studies. Her research interests lie at the intersection of social studies of science and technology, surveillance studies, critical algorithm studies, and pragmatic ethics. She is an expert in the social and ethical implications of cutting-edge genetic and genomic technologies for human identification. Helena was the Principal Investigator of the Exchange project, which explored political processes related to genetic state surveillance and the role of genetics in the fabric of suspicion. Her research also covers topics such as regimes of expertise, ethics in controversial genetic issues, national borders enacted through DNA data, and the power structures behind genetic technologies.



Dr Vanessa Lynch is a leader in the field of Forensic DNA policy, with a wealth of experience leading nationwide policy initiatives. As the Regional Director of DNAforAfrica and Senior Government Affairs Consultant with GTH-DNA, she collaborates with agencies throughout Africa to promote advocacy outreach and forensic expertise for the development of DNA databases and casework programs. Vanessa founded The DNA Project in 2005 and launched DNAforAfrica in 2021, demonstrating her unwavering commitment to advancing dynamic legislative and policy changes across the continent. Her expertise and contributions have earned her numerous accolades, including recognition for her leadership in driving the adoption of legislation to administer South Africa's National Forensic DNA Database - the first of its kind in Africa. As Deputy Chair of the National Forensic Oversight and Ethics Board (SA), she played a pivotal role in overseeing the implementation of the provisions of the DNA Act in its first five years. Vanessa also serves on the DNA Forensic DNA Policy Board for Africa, where she advocates for the development of workable forensic DNA policies in Africa.