Symposium

Biobanks and biomedical collections

An ethical framework for future research

Strasbourg, 19-20 June 2012

COUNCIL OF EUROPE CONSEIL DE L'EUROPE

Tuesday 19 June 2012

8.30 – 9.30 **Registration**

Opening

Chairs:

Prof. Eugenijus Gefenas, Chair of the Committee on Bioethics (DH-BIO), (Lithuania)
Mr Jan Kaźmierczak, General Rapporteur on Science and Technology Impact Assessment (Parliamentary Assembly of the Council of Europe)

9.30 – 9.40 **Mr Philippe Boillat**, Director General, Directorate General Human Rights and Rule of Law, Council of Europe

9.40 – 9.50 **Dr Octavi Quintana Trias**, Director of the European Research Area, European Commission

9.50 – 10.00 **Introduction**

Dr Anne Forus, Chair of the Coordination Group for the organisation of the symposium (Norway)

Session 1 – **Biobanks: situation and expectations**

Chairs:

Dr Anne Forus, Chair of the Coordination Group for the organisation of the symposium (Norway)
Dr Lino Paula, Directorate-General of Research and Innovation, European Commission

10.00 – 10.35 Overview of the situation regarding research biobanks

Prof. Milan Macek, Head of the Department of Biology and Medical Genetics, Charles University Prague, member of the European Commission Expert Group on biobanks (Czech Republic)

Questions

10.35 –11.10 Public understanding and expectation regarding biobanking

Prof. Herbert Gottweis, Chair of the European Commission Expert Group on biobanks, Professor, Department of Political Science, University of Vienna (Austria)

Questions

11.10 – 11.40 *Break*

Session 2 – Information and consent as a process

Chairs:

Dr Emmanuelle Rial-Sebbag, member of the European Commission Expert Group on biobanks (France)
Prof. Dr Elmar Doppelfeld, member of the Coordination Group for the organisation of the symposium (Germany)

11.40 –12.00 Main challenges

Prof. Bartha Knoppers, Director of the Centre of Genomics and Policy, Faculty of Medicine, McGill University (Canada)

12.00 – 12.15 Information process (quantity, quality, dynamics)

Prof. Christian Chabannon, Director of the Cancer Biobank, Institute Paoli-Calmettes, Marseille (France)

12.15 – 12.30 Recontacting – Consenting again

Prof. Christian Scerri, Associate Professor, Department of Physiology and Biochemistry, University of Malta (Malta)

12.30 – 12.45 Protection of vulnerable persons: the case of children

Prof. Martina Cornel, Professor of Community Genetics and Public Health Genomics, VU University Medical Center, Amsterdam (Netherlands)

12.45 – 13.30 Discussion

13.30 – 15.00 Lunch break

Session 3 – Privacy and data protection

Chairs:

Dr Siobhán O'Sullivan, member of the Coordination Group for the organisation of the symposium (Ireland)
Prof. Graeme Laurie, member of the Coordination Group for the organisation of the symposium (United Kingdom)

15.00 –15.20 Main challenges

Dr Roberto Lattanzi, Head of Unit, Italian Data Protection Authority, member of the European Commission Expert Group on biobanks (Italy)

15.20 –15.35 Limits of anonymisation

Dr Pilar Nicolàs, Research projects co-ordinator, Inter-University Chair in Law and the Human Genome, University of Deusto, University of the Basque Country (Spain)

15.35 – 15.50 Transborder flows of samples and accompanying data

Prof. Kurt Zatloukal, Institute of Pathology, Medical University of Graz, Coordinator of BBMRI (Austria)

15.50 –16.05 Right to withdraw consent – right to be forgotten
Prof. Elisabeth Rynning, Professor of Medical Law, Uppsala University (Sweden)

16.05 – 17.00 Discussion

Wednesday 20 June 2012

Session 4 – Responsible governance and use

Chairs:

Dr Jane Kaye, Rapporteur of the European Commission Expert Group on biobanks (United Kingdom)
Dr Javier Arias-Diaz, member of the Coordination Group for the organisation of the symposium (Spain)

9.00 – 9.20 Mechanisms for internal biobank governance - Oversight bodies and independent ethics bodies

Prof. Graeme Laurie, Director of Research, School of Law, University of Edinburgh (United Kingdom)

9.20 – 9.40 Access (fairness of access, transparency, criteria, biobank networks)

Prof. Kristian Hveem, Director of the HUNT Biobank (Norway)

9.40 – 10.00 Feedback (right/obligation, mechanism)

Prof. Andres Metspalu, Head of the Estonian Genome Center (Estonia)

10.00 – 10.45 Discussion

10.45 – 11.15 Break

Session 5 – General roundtable

Moderator: **Mr Dick Ahlstrom,** Science Editor of the Irish Times (Ireland)

11.15 – 12.45 Discussion about key issues identified during symposium

Private biobank: **Dr Björn Dahllöf**, Executive Director, Biobanking & Sample Management, Novartis (Switzerland)

Patients/donors: **Dr Monica Ensini**, Registers and Biobanks Senior Manager, EURORDIS (Rare Diseases Europe), (France)

Biobanks networks: **Prof. Bartha Knoppers**, Chair, Public Population Project in Genomics (P3G), (Canada)

Biobank manager: **Dr Bob Phillips**, Director General of Integrated BioBank of Luxembourg (Luxembourg)

User: **Prof. Alexander Tonevitsky**, Head of the Laboratory of Molecular Physiology in the Institute of General Pathology and Pathophysiology of the Russian Academy of Medical Sciences (Russian Federation)

Competent authorities: **Dr Anneli Törrönen,** Ministerial Advisor, Ministry of Social Affairs and Health (Finland) / **Dr Martin Götz**, Scientific expert, Biomedicine Division, Federal Office of Public Health (Switzerland)

Population Biobanks: **Prof. Erich Wichmann**, Spokesperson of the Epidemiological Planning Committee (EPC) of the German National Cohorte, German Coordinator of the European Biobanking and Biomolecular Resources Research Infrastructure (BBMRI), (Germany)

Ethics committee: **Dr Nikolajs Zeps**, Research group leader, St. John of God Healthcare, member of the Australian health ethics committee (Australia)

12.45 – 13.15 **Conclusions**

- Summary of main issues raised: Secretariat
- Follow up: **Dr Anne Forus**, Coordinator
- Closing