Second International Conference of the Tiss.EU Project

PRIVACY, CONFIDENTIALITY & PERSONALITY RIGHTS IN BIOBANKING AND GENETIC RESEARCH WITH HUMAN TISSUE

University Medical Center Goettingen, Germany, July 16th - 18th, 2009

CONFERENCE VENUE:
UNIVERSITY LIBRARY OF GOETTINGEN
PLATZ DER GÖTTINGER SIEBEN 1, 37073 GOETTINGEN

ORGANISED BY:
Department for Medical Ethics and History of Medicine
Dr Christian Lenk, Dr Katharina Beier, Prof Dr Claudia Wiesemann (Goettingen University), and Dr Nils Hoppe (Hannover University)

WITH INPUT FROM THE PROJECTS
GENEBAnc (LEUVEN) AND PRIVILEGED (MAASTRICHT/SHEFFIELD)

PROGRAMME

THURSDAY, 16 JULY
3:00 – 3:30 P.M.: Registration & Welcome Refreshments
3:30 – 4:00 P.M.: Introduction to the project

PANEL I: PRIVACY & CONFIDENTIALITY IN BIOBANK-RELATED RESEARCH
4:00 – 5:00 P.M.: Dave Townend, PRIVILEGED, Sheffield, UK
Protecting Privacy in Research using Genetic Information and Biobanking
5:00 - 6:00 P.M.: Mats G. Hansson, Centre for Research Ethics & Bioethics, University of Uppsala, Sweden
Privacy and health research using biobanks
6:00 - 7:00 P.M.: LEISURE
7:00 – 8:00 P.M.: BUFFET DINNER AT “CAFÉ BOTANIK”

FRIDAY, 17 JULY
9:00 A.M.: Welcome Address (N.N.)
9:15 - 10.00 A.M.: Georg Lauß, Dept. of Political Science, University of Vienna, Austria
(Dis-)Entangling Public and Private Zones in Biobank Research: A conceptual and theoretical framework
10.00 – 11.00 A.M.: Lars Øystein Ursin, Dept. of Philosophy, Norwegian University of Science and Technology, Trondheim, Norway
Privacy and property in commercial biobanking
11.00 – 11.30 A.M.: COFFEE BREAK
PANEL II: PRIVACY, CONFIDENTIALITY & PERSONALITY RIGHTS: LEGAL & ETHICAL PERSPECTIVES ON HUMAN TISSUE RESEARCH

11:30 – 12:15 A.M.:  
Judit Sándor, Center for Ethics and Law in Biomedicine, Central European University Budapest, Hungary  
Private Tissues?

12:15 – 1:00 P.M.:  
Martin Sebastian Haase, University of Hannover, Germany  
Data protection within medical research – Personal reference of data resulting from human tissue research

1:00 – 2:15 P.M.:  
LUNCH

2:15 – 3:15 P.M.:  
Kris Dierickx, GeneBanC, Centre for biomedical ethics and law, Catholic University Leuven, Belgium  
GeneBanC: biobanks between privacy and harmonisation

3:15 – 4:00 P.M.:  
José Miola, Faculty of Law, University of Leicester, UK  
Privacy, Confidentiality, Anonymisation, and Human Rights – A UK Lawyer’s Perspective

4:00 – 4:30 P.M.:  
Coffee Break

4:30 – 5:30 P.M.:  
Marion Albers, Lehrstuhl für Öffentliches Recht, Wirtschafts-, Informations-, Gesundheits- und Umweltrecht, Universität Augsburg, Germany  
Personality Rights, biobanking and data from genetic research (title to be confirmed)

5:30 – 7:30 P.M.:  
Leisure

7:30 P.M.:  
Conference Dinner at “Kartoffelhaus”

PANEL III: QUESTIONS OF APPLICATION AND MODELS OF REGULATION

9:30 – 10:15 A.M.:  
Paul Chummar, The Catholic University of Eastern Africa, Kenya  
In search of Ethical Principles for Tissue Research and Protection of Vulnerable Populations on the Basis of Medical Anthropological Foundations

10.15 – 11.00 A.M.:  
Claudio Tamburrini, Centre for Healthcare Ethics, Stockholm University, Sweden  
What’s wrong with Forensic Data Bases?

11.00:  
Coffee Break

11.30 – 12:15 A.M.:  
Christina Schröder, Fraunhofer IBMT, Potsdam-Golm, Germany  
Safeguarding donors’ personal rights and biobanks’ autonomy in biobank networks: The CRIP Privacy Regime

12.15 – 1:00 P.M.:  
Concluding Remarks & Closing of Conference

1:00 P.M.:  
Light Snack & Farewell

SATURDAY, 18 JULY