



UNIVERSITÀ DEGLI STUDI
DI MILANO

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Collecting biological tissues and DNA specimens in order to create and manage biobanks, together with the creation of a database dealing with individuals' clinical information, is becoming a common practice with increasingly relevance in basic and clinical biomedical research.

As a consequence, we are facing unprecedented ethical, social, legal and governance dilemmas that require new tools for an effective and legitimate use of these data with the aim of both preserving the needs of research and granting collective and individual rights.

The adequacy of the usual consents, privacy protection and the treatment of personal data have to be reshaped, taking into account the peculiarities of the biomedical research in the post-genomics era. In particular, a new idea of autonomy has to be proposed.

The international workshop on "Rethinking Autonomy in the Research Biobanks Age" wants to offer a timely opportunity for a debate among internationally leading experts who present the state-of-the art on research-biobanks and suggest topics for legal and ethical considerations.



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UNIVERSITÀ
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*Ethical
Committee*

RETHINKING AUTONOMY IN THE RESEARCH BIOBANKS AGE

December 17-18, 2009

*Università degli Studi
di Milano
Aula Magna
Via Festa del Perdono 7
20122 Milano*

*International
Meeting
organized in
cooperation with*



FONDAZIONE
CENTRO NAZIONALE
DI PREVENZIONE E
DIFESA SOCIALE

DECEMBER 17

13.30 REGISTRATION

14.00 OPENING

E. Decleva, *Rector of the Università degli Studi di Milano*;
V. Ferrari, *Chair of the Ethical Committee of the Università degli Studi di Milano*;

G. Coggi, *M.D., F.R.C.Path. Professor of Pathology and Chairman, Università degli Studi di Milano Medical School*;
L. Pomodoro, *President of the Court of Milan and Secretary-General of the Fondazione Centro Nazionale di Prevenzione e Difesa Sociale - CNPDS*

SESSION I - SCIENTIFIC ASPECTS

Chair: M. Cocucci, Professor of Plant Physiology and Member of the Ethical Committee of the Università degli Studi di Milano

15.00 P. P. Di Fiore, *Professor of General Pathology, Università degli Studi di Milano and Fondazione IFOM-FIRC Institute of Molecular Oncology (Milano)*, "The Relevance of Biobanks to Molecular Medicine "

15.30 M. Filocamo, *Director of Laboratorio Diagnosi Pre-Postnatale Malattie Metaboliche of the Istituto G. Gaslini (Genova)*, "Genetic Biobank Network"

16.00 G. McVie, *Senior Consultant of the European Institute of Oncology (Milano)*, "Communications challenges in biobanking - eurocancercoms is a solution"

16.30 BREAK

SESSION II - SURVEYING RESEARCH BIOBANKS IN THE MILAN AREA
Chair: P. M. Mannucci, Professor of Medicine and Member of the Ethical Committee of the Università degli Studi di Milano

16.45 P. Rebullà, *MD, Director of the Center of Transfusion Medicine, Cellular Therapy and Cryobiology - Department of Regenerative Medicine, Fondazione Ospedale Maggiore Policlinico, Mangiagalli e Regina Elena (Milano)*, "The case of the Policlinico Cord Blood Bank"

17.15 S. Pece, *Professor of General Pathology, Università degli Studi di Milano and Fondazione IFOM-FIRC Institute of Molecular Oncology (Milano)*, "The case of the IEO cancer bank"

17.45 M. Pierotti, *PhD, Scientific Director of the Istituto Nazionale dei Tumori (Milano)*, "Towards a virtual regional biobank in the context of the Regional Oncological Network (ROL)"

18.15

DECEMBER 18

SESSION III - ETHICAL ASPECTS

Chair: L. Boella, Professor of Moral Philosophy and Member of the Ethical Committee of the Università degli Studi di Milano

9.00 A. Cambon-Thomsen, *Research Director in French National Center for Scientific Research (CNRS)*, "Sharing of bioresources as a strategic and ethical milestone in biobanking"

9.30 B. Elger, *Professor of Ethics and Health Law, Center for Legal Medicine, University of Geneva*, "Autonomy of sample donors: results from an international study"

10.00 M. G. Hansson, *Professor of Biomedical Ethics and Director of the Centre for Research Ethics and Bioethics at Uppsala University and Karolinska Institutet*, "The need of a more generous view of autonomy on ethical review boards"

10.30 BREAK

SESSION IV - LEGAL ASPECTS

Chair: M.C. Tallacchini, Professor of Legal Philosophy, Università Cattolica del Sacro Cuore, sede di Piacenza and Member of the Ethical Committee of the Università degli Studi di Milano

10.45 R. Chadwick, *Director of the Centre for Economic and Social Aspects of Genomics, Cardiff University*, "Consent: from 'narrow' to 'broad' to 'open'"

11.15 R. Lattanzi, *PhD, Italian Data Protection Authority, Seconded national expert, European Data Protection Supervisor*, "Data Protection Principles and Research in the Biobanks Age"

12.45 P. Zilgalvis, *J.D, Head of Unit, L3, Governance and Ethics, European Commission; Research Directorate - General; Directorate L - European Research Area: Science, Economy and Society*, "Research Access to Biobanks While Safeguarding Fundamental Rights"

13.15 CLOSING

G. Boniolo, *Professor of Philosophy and Medical Humanities, Università degli Studi di Milano and Fondazione IFOM-FIRC Institute of Molecular Oncology (Milano) and Member of the Ethical Committee of the Università degli Studi di Milano*

13.30

* Every speech will be followed by a 10 minutes' question time

MEETING

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Scientific and organisational secretariat
Fondazione Centro Nazionale di Prevenzione e Difesa Sociale
Palazzo Comunale delle Scienze Sociali
Piazza Castello 3, 20121 Milano
Tel. +39 0286460714
Fax +39 0272008431
E-mail: cnpds.ispac@cnpds.it
Web site: www.cnpds.it