



UNIVERSITY OF OSLO

Center for Medical Ethics

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FACULTY OF MEDICINE

Ethical Challenges in gene-epidemiological research and health registry research Oslo, August 20 – 21, 2004 Program

August 20

- 08.30-09.15 The concept of goodness in health related research
Lecturer: Jan Helge Solbakk
- 09.15-09.30 Break
- 09.30-10.15 Prevalent misapprehensions in the debates on regulating genetic medicine (*genetic exceptionalism, genetic determinism, genetic overgeneralization, the statistical overestimation of uncertainty, the obsession with drawing moral lines and boundaries*)
Lecturer: Jan Helge Solbakk
- 10.15-11.00 Discussion/Coffee
- 11.00-11.45 Autonomy: ethical guideline or rhetorical rubbish?
Lecturer: Bjørn Hofmann
- 11.45-12.00 Discussion
- 12.00-13.30 Lunch
- 13.30-14.15 The state of the art of international research ethics – part 1
Lecturers: Søren Holm and Jan Helge Solbakk
- 14.15-14.30 Break
- 14.30-15.15 The state of the art of international research ethics – part 2
Lecturers: Søren Holm and Jan Helge Solbakk
- 15.15-16.00 Discussion/Coffee

August 21

- 08.30-09.15 Informed consent: a practical procedure or misguided ideal in gene-epidemiological research and health registry research? – part 1
Lecturers: Anne Cambon-Thomsen and Bartha Maria Knoppers
- 09.15-09.30 Break
- 09.30-10.15 Informed consent: a practical procedure or misguided ideal in gene-epidemiological research and health registry research? – part 2
Lecturers: Anne Cambon-Thomsen and Bartha Maria Knoppers
- 10.15-11.00 Discussion/Coffee
- 11.00-11.45 Genetic information and genetic privacy (*autonomy and the duty to keep oneself genetically informed, autonomy and the right to genetic ignorance*)
Lecturers: Jan Helge Solbakk
- 11.45-12.00 Discussion
- 12.00-13.30 Lunch
- 13.30-14.15 The institutional nature of research biobanks
Lecturers: Søren Holm and Roger Strand
- 14.15-14.30 Break
- 14.30-15.15 Use of biobank materials – access-rights, data protection, confidentiality and regulation of research projects – part 1
Lecturers: Bartha Maria Knoppers and Anne Cambon-Thomsen
- 15.15-15.30 Break/Coffee
- 15.30-16.15 Use of biobank materials – access-rights, data protection, confidentiality and regulation of research projects – part 2
Lecturers: Bartha Maria Knoppers and Anne Cambon-Thomsen
- 16.15-17.00 Discussion

About the lecturers:

1) Anne Cambon-Thomsen, MD, Director of Research at Centre National de la Recherche Scientifique (CNRS) and Head of a research group in an Inserm Unit on “Epidemiology and analyses in public health” at the University of Toulouse III, Toulouse, France.

2) Bartha Maria Knoppers, B.A, M.A, LL.B., B.C.L., D.L.S, Canada Research Chair in Law and Medicine, Professor at the Faculté de droit, Université de Montréal and Senior Researcher at the Centre for Public Law (C.R.D.P.), Canada.

3) Bjørn Hofmann, M.Sc. (physics, electronics and biomedical engineering), Ph.D (medical ethics), Assistant Adjunct Professor and postdoctoral fellow, Center for Medical Ethics, Faculty of Medicine, University of Oslo, Norway.

4) Søren Holm, B.A., M.A., M.D., Ph.D., Dr.Med.Sci., Professorial Fellow in Bioethics Cardiff Law School, Cardiff University, Cardiff, Wales and Adjunct Professor of medical ethics, Center for Medical Ethics, Faculty of Medicine, University of Oslo, Norway.

5) Jan Helge Solbakk, MD, Th.M, Dr. philos, Professor and Director, Center for Medical Ethics, Faculty of Medicine, University of Oslo, Norway, and Adjunct Professor of medical

ethics and philosophy of medicine, Center for International Health, Faculty of Medicine, University of Bergen, Norway.

6) Roger Strand, M. Sc. (biochemistry), dr.scient (philosophy of science), post-doctoral fellow, Centre of the Study of the Sciences and the Humanities, University of Bergen.