



Nordic Biobank Research Obstacles and Opportunities

Uppsala Konsert & Kongress
3–4 May 2011

Photo: HUNT Biobank, Norway

The Nordic countries have a long history of utilising biological samples, patient records and health registers to study disease in the population and develop new forms of intervention, treatments and medications. Biobanking, however, raises ethical questions on how to address integrity, privacy, access, legislation and protection from information excess in light of the possibilities to understand and treat diseases using new technology.

>> www.ncbio.org



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Nordic Committee on
Bioethics



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BioBanking and
Molecular Resource
Infrastructure of
Sweden

This conference is arranged by the Nordic Committee on Bioethics together with the Centre for Research Ethics & Bioethics at Uppsala University and BioBanking and Molecular Resource Infrastructure of Sweden (BBMRI.se)

Day 1 Tuesday May 3, 2011

- 13.00-14.00 **Registration**
- 14.00-14.10 **Opening and welcome**
Aaro Tupasela, chair Nordic Committee on Bioethics

Biobanking today

Chair: *Göran Elinder*

- 14.10-14.40 **State of the art of international biobank research**
Kristian Hveem, Professor, Norwegian University of Science and Technology
- 14.40-15.00 **Benefits of biobank research**
Helena Kääriäinen, Professor, National Institute for Health and Welfare, Finland
- 15.00-15.20 **Biobanking and legislation. Overview on current trends and challenges**
Sirpa Soini, National Institute for Health and Welfare, Finland
- 15.20-15.40 **Discussion**
- 15.40-16.00 **Coffee**

Biobanking and legislation

Chair: *Janne Rothmar Herrmann*

- 16.00-16.20 **Risks of biobank research**
Jan Helge Solbakk, Professor, Section for Medical Ethics, Faculty of Medicine, University of Oslo
- 16.20-16.40 **Collecting samples for future uses. Case: Opt-out in the Danish biobanking**
Mette Hartlev, Professor, Faculty of Law, University of Copenhagen
- 16.40-17.00 **Biobank samples and personal data – navigating the legal crossroads of registry research**
Elisabeth Rynning, Professor, Faculty of Law, Uppsala University
- 17.00-17.20 **Council of Europe recommendation on Biobanks. Experiences and re-examination after five years of adoption**
Laurence Lwoff, Bioethics Division, Council of Europe, Strasbourg
- 17.20-18.00 **Discussion**

Day 2, Wednesday May 4, 2011

Autonomy

Chair: *Ásgeir Haraldsson*

- 9.00 – 9.20 **Is there a need of a wider view of autonomy for biobank based research and what does it then entail, e.g regarding informed consent and ethical review?**
Mats G. Hansson, Professor, Centre for Research Ethics & Bioethics, Uppsala University
- 9.20 – 9.40 **Integrating clinical and research biobanks in the academic setting**
Magnús Karl Magnússon, Professor, Faculty of Medicine, University of Iceland
- 9.40 – 10.00 **Discussion**

Trust and privacy in biobanking

Chair: *Anne Myhr*

- 10.00 – 10.20** **Trust and duty in health care-related biobanks: Are informed consent procedures letting patient-donors down?**
Linus Johnsson, MD, PhD Student, Centre for Research Ethics & Bioethics, Uppsala University
- 10.20 – 10.40** **Investment, engagement and coincidence: multiple meanings of participation in biobanks**
Karoliina Snell, Researcher, Department of Social Science, University of Helsinki
- 10.40 – 11.00** **Discussion**
- 11.00-11.30** **Coffee**

Individual rights or public goods?

Chair: *Gunhild Isfeldt*

- 11.30-11.50** **Will be announced**
Heidi Thorstensen, Oslo University Hospital
- 11.50-12.10** **In defence of the public rights, goals and trust**
Angus Dawson, Senior Lecturer, Centre for Professional Ethics, Keele University
- 12.10-12.30** **Discussion**
- 12.30-13.30** **Lunch**

Biobanks and the future

Chair: *Grethe Foss*

- 13.30-14.00** **Is ethical review of biobank based research up to date?**
Simon N. Whitney, Professor, Department of Family and Community Medicine, Baylor College of Medicine, Houston, TX.
- 14.00-14.20** **How to combine information from health registry and biobanks with information collected for research within the university.**
Göran Elinder, Senior Professor, Karolinska Institutet, Stockholm
- 14.20-14.40** **Biobank research and the decisions of ethics review boards in Sweden**
Joanna Stjernschantz Forsberg, MD, PhD Student, Centre for Research Ethics & Bioethics, Uppsala University
- 14.40-15.10** **Incidental findings and new technologies**
Kári Stefánsson, MD, Dr Med, Chairman and CEO, deCODE genetics, Iceland
- 15.10-15.45** **Panel discussion**
- 15.45-16.00** **Concluding remarks**
Mats G. Hansson, chair Centre for Research Ethics & Bioethics



Foto: Jens Norberg

For more information about the conference contact the organizing committee:

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The *Nordic Committee on Bioethics* was established in 1989 to promote Nordic cooperation and exchange of information between scientists, parliamentarians, opinion leaders and public officials in the area of bioethics.

For further information: www.ncbio.org

The *Centre for Research Ethics & Bioethics* (CRB) is an interfaculty centre at Uppsala University.

For further information: www.crb.uu.se

The *BioBanking and Molecular Resource Infrastructure of Sweden* is a national effort for efficient and automated collection of biological material.

For further information: <http://bbmri.se/en/>



Photo: Kalbar/Uppsala Tourism

General information:

Meals

The coffee breaks will take place at level 3. Lunch Wednesday will be served on the ground floor.

Tourist information

For further information about Uppsala, please contact:

Uppsala Tourist Office
Fyristorg 8
753 10 Uppsala
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Venue

Uppsala Concert & Congress Hall (Uppsala Konsert & Kongress)
Visiting address: Vaksala torg 1
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