Workshop

Biobank Research Across the Nordic Countries: Ethical, Legal and Societal Perspectives

The workshop will explore how biobank research can be conducted collaboratively across the Nordic countries – addressing legal frameworks, informed consent, and societal trust. The workshop is organized by the Faroese Health Authority in collaboration with the Nordic Biobank Network (NBN).

Faroe Islands | 2–3 June 2026

Starvsfelagshúsið, J. H. Schrøtersgøta 9, 100 Tórshavn

Programme

Day 1 – Tuesday, 2 June

09:00–09:30

Light breakfast and arrival

Coffee/tea available throughout the day

09:30–09:50 Welcome and opening remarks

Welcome by Noomi O. Gregersen, Director of the Faroese Health Authority and Isabelle Budin Ljøsne, Chair of Activity 5 ELSI, Nordic Biobank Network

Opening remarks by Ása Olsen, Chair of MEGD

Session 1 – Legal Frameworks & Data Access Procedures

This session explores legal foundations for cross-border data access and governance in the Nordic countries.

Session Chair: Erik Sørensen, Head of Operations, Copenhagen Hospital Biobank Unit, Copenhagen University Hospital, Rigshospitalet, Denmark

09:50–10:20 Comparative overview of biobank access procedures and legislation in the Nordic countries

Johanna Mäkelä, Director of Research and Services & Tom Southerington, Chief Legal Officer, Finnish Biobank Cooperative (FINBB), Finland

10:20–11:00 Panel discussion with Nordic Biobank Network representatives

Comparison and discussion of results from survey

11:00–11:10 Short break

Refreshments

11:10–12:15 Plenary discussion

Case study: How to enable biobank research collaboration across the Nordic countries when different national rules apply?

12:15–13:00 Lunch break

Session 2 – Informed Consent in Practice

This session discusses consent as a basis for secondary use and cross-border research

Session Chair: Estrid Høgdall, Head of Secretariat, Regional Bio- and Genome Bank, Denmark

13:00–13:20 Web portal for information on use of samples

Erik Sørensen, Head of Operations, Copenhagen Hospital Biobank Unit, Copenhagen University Hospital, Rigshospitalet, Denmark

13:20–13:40 Patient perspectives on broad consent – the case of Norway

Isabelle Budin Ljøsne, Senior Researcher, Norwegian Institute of Public Health, Norway

13:40–14:30 Country presentations from Nordic Biobank Network representatives

14:30–14:50 Short break

Refreshments

14:50–15:50 Plenary discussion

Case study: Broad consent and changing research topics.

How far does consent extend?

15:50–16:15 Closing of Day 1

Summary of key conclusions

Framing of Day 2: From legal and consent frameworks towards broader societal and ethical considerations in cross-border research.

Day 2 – Wednesday, 3 June

09:00–09:30

Light breakfast and arrival

Coffee/tea available throughout the day

Session 3 – Ethical & Societal Aspects

This session will explore ethical and societal challenges in cross-border biobank research, including trust, identifiability, and proportionality

Session Chair: Isabelle Budin Ljøsne, Senior Researcher, Norwegian Institute of Public Health, Norway

09:30–09:50 Conducting research in small communities: Trust, proximity, identifiability, and proportionality – The case of the Faroe Islands

Noomi Oddmarsdóttir Gregersen, Director, the Faroese Health Authority; Project manager, FarGen, Faroe Islands

09:50–10:30 Country presentations from Nordic Biobank Network representatives

10:30–11:10 Plenary discussion

Case study: Nordic data in a European research project

Do consent and trust still hold?

11:10–11:30 Closing session

Summary of key conclusions

Formal closing of the workshop

11:30–12:00 Lunch

12:00 Official end of the workshop