Guidelines for administration and use of research data from The Nord-Trøndelag Health Study (HUNT)

The guidelines for The Nord-Trøndelag Health Study have been in use since the time of HUNT 2 (1995-1997). The guidelines are revised several times, to adjust to changes in legislation, organisation and administrative practices at the HUNT Research Centre, NTNU. This version of the guidelines is current from March 23rd, 2015.

The Norwegian version of the guidelines contains more detailed descriptions and explanations of the guidelines, and need to be referred to in case of doubt.

1. Why guidelines for administration and use of HUNT research data?
The purpose of these guidelines is to optimise utilisation of HUNT research data, promote collaboration, and avoid potential conflicts by safeguarding the interests of participants and researchers involved.

2. Ethics and protection of the participants’ privacy
Research with data from HUNT must always respect the participants’ privacy, and comply with research ethics and with Norwegian rules and regulations.

3. Ownership and right of disposal
The HUNT participants, i.e. those who have contributed with data and samples, are the owners of the collected data and biological material. Only the person who has donated data/biological material can demand the data/biological material deleted/destroyed. The Faculty of Medicine at NTNU has the right of disposal. This implies that the Faculty of Medicine can enter into contracts of rights to access and analysis of HUNT data and biological material, but the data or biological material itself cannot be subject to transfer or sale.

4. Contracts are entered into with Research Institutes
This makes institutes, not single researchers, responsible contract partners. Research institutes appoint a Principal Investigator for each project.

5. Exclusive contract on research topics
Contracts define exclusive rights to analyse the research questions as described in a research protocol and defined precisely in a publication plan.

6. Contracts are delimited in size and period
Contracts are delimited in scope and period. A PhD project is used as a template, typically with 3-4 publications in 4 years as a standard. When an application contains only one publication the contract period is usually set to two years.

7. Presentation of manuscript to the publication committee
All manuscripts (articles, reports and abstracts) must be submitted to HUNT Research Centre before they are submitted to a journal. The purpose of this rule is to make sure that all results from The HUNT Study are published in accordance with the contract.
8. Co–authorship
The Principal Investigator is responsible for the composition of the author group. It is a presumption that the Vancouver rules for authorship are followed.

9. Daily administrative duties
The Dean of The Faculty of Medicine is responsible for HUNT material and the use of it on behalf of NTNU. The daily administrative duties are delegated to the General Manager of HUNT Research Centre.

10. Whole HUNT Databank united
All data in HUNT Databank, i.e. data collected in HUNT1, HUNT2, HUNT3, YoungHUNT included, additional projects, and biological material is managed according to the same guidelines.

11. Research data shall be returned or deleted or destroyed by the end of the project
Results from new analyses on HUNT material, e.g. genotyping or other laboratory analyses, and other “new” variable constructions based on original HUNT variables shall be returned to HUNT Databank. When the project is ended the data file must be returned or confirmed deleted, leftover biological material shall be destroyed if nothing else is agreed upon.

12. Priority to researchers responsible for additional projects
Also data collected in additional projects in HUNT is managed by the Dean of The Faculty of Medicine, NTNU. Researchers responsible for data collection in such projects are granted an exclusive right of use over the data collected for a 5-year period. The usual application procedure applies when data from additional projects are used in combination with other HUNT data.

13. No commercial utilization
Access to research data or biological material originating in The HUNT Study does not include any rights to commercial use.

14. Costs for the use of HUNT datafiles
To ensure the organization and continuation of HUNT Databank, i.e. including development and quality assurance, The Faculty of Medicine at NTNU has decided that HUNT Research Centre charge a cost for projects using HUNT material. Current costs are published on our website: http://www.ntnu.no/hunt/priser

15. Costs for the use of biological material
An additional cost for the use of biological material applies. Cost estimates for different types of samples can be found at our website: http://www.ntnu.no/hunt/biomateriale.

These guidelines are a translation of the Norwegian “Retningslinjer for forvaltning og bruk av data og biologisk materiale fra Helseundersøkelsen i Nord-Trøndelag”. No rights can be derived from this translation. In the case of doubt, the Norwegian guidelines are to be referred to.

For more information, see the guidelines for administration and use of data from The Nord-Trøndelag Health Study complementary commentaries [in Norwegian only].