

HUNT 3

Declaration of Consent form + 2nd to last page of the brochure

Consent

Participation in HUNT 3 and other public health studies is voluntary. The information from the health study cannot be used for research without the consent of the participants. You will be asked to sign a declaration of consent when you participate. Information and samples that you give will be stored for an indefinite time period. In the future it may be used in studies that as of yet have not been planned provided the studies are in accordance with laws and regulations.

In the future, you will be informed about new research projects that use HUNT data. This information can be found at www.hunt.ntnu.no, and in addition, once a year written information will be sent out to the public. There will also be media coverage about some of the research projects.

You can, at any time after the health study, withdraw your consent and ask that the data about you is deleted or that your blood and urine samples be destroyed. If you wish to withdraw your consent, contact HUNT Research Centre, Neptunveien 1, 7650 Verdal, Telephone 74 07 51 80, Fax 74 07 51 81 or their e-mail: hunt@medisin.ntnu.no. We will respect your wishes to not use your information in specific research projects if you request this.

New Consent

If in the future we need your information for new types of research questions not described in this brochure, it may be necessary to ask for a new declaration of consent. If this is the case, we will send you a letter. You may also be asked for a new consent in the eventuality of a collaboration with a private company in genetic research. The research of this type of collaboration must also adhere to public laws and regulations. Under no circumstances will blood or other biological material be sold.

Personal Information Protection and Security

All information that you give to HUNT 3 will be handled with respect to personal information protection and your private life and in accordance with the laws and regulations. As soon as information, blood samples and/or urine samples are collected, they are stored without being labelled using the identity of the donor. Researchers who later use the information do not have access to names, birthdates or personal identification numbers. All employees associated with the health study have an obligation of confidentiality.

The Data Inspectorate supervises to ensure that the laws and regulations concerning the storage and use of health care information are followed. HUNT 3 is licensed by the The Data Inspectorate.

Ethical Approval

All research projects must be approved by an ethical committee. The committee is an independent agency that evaluates the ethical aspect of research projects. HUNT 3 has been approved by The Regional Committee for Medical Research Ethics, Mid-Norway. All future research projects that use data from HUNT must gain approval from the committee.

HUNT Databank

HUNT databank contains information collected during HUNT 1, 2 and 3 by means of questionnaires, examinations and analyses of blood and urine samples. If you participated in HUNT 1 and 2, your information will be compared to information in HUNT 3. Genetic material is stored at the HUNT biobank. The goal of the biobank is that in the future it will be possible to take out samples, perform various analyses and compare it to the results of other data from the HUNT databank. In this way there will be continuously more data to be put into the databank.

When researchers receive data from the HUNT databank there are no names, birthdates or other identifiable characteristics with the data, so they do not know who gave the information.

Comparing Information from other Registers

For certain research projects it may be necessary to compare data from HUNT with other public records, for example The Norwegian Prescription Database, The Birth Register, The Cancer Register and The Cause of Death Register. HUNT data may also be compared to other registers/databases at Statistics Norway (SSB), for example concerning the environment, population, education, income, public contribution, employment and other situations that may have an effect on health.

In addition, it may also be relevant to obtain diagnosis information, for example hip fracture, heart attack, stroke or lung illnesses from primary health care, the hospitals in Nord-Trøndelag or St. Olavs hospital. Some projects may compare information of parents, children, siblings and grandparents if they have participated in HUNT.

All these comparisons require consent and/or approval from the applicable agencies, for example The Regional Committee for Medical Research Ethics, The Data Inspectorate, The Public Health Department or Social Security. All information will be handled with respect to personal information protection and your private life and in accordance with the laws and regulations. No researchers will know who gave the information.

Compensation

There is very little risk that participation will lead to injury. If this should occur, compensation can be applied for through The Norwegian System of Compensation to Patients (NPE). NPE facilitates compensation applications for patients who have been injured in the public health care service system.

Young HUNT

All adolescents in the age group 13 to 19 years old in Nord-Trøndelag are invited to participate in Young HUNT. The project will take place at their schools, with the filling out of the questionnaire and clinical examinations occurring during school hours. Adolescents and their parents will receive information about Young HUNT through the school.

Declaration of consent for use of health information in research

The Nord-Trøndelag Health Study 2006-2008 (HUNT3)

In the brochure I received I have read about the health study's content and intent, and I have been given the opportunity to ask questions.

I consent to participating in the study.

Place, date time

Name

Date of Birth