

An invitation to participate in SAMINOR 3

What is SAMINOR?

SAMINOR is a population-based study of health and living conditions in regions with Sami and Norwegian populations. This study will provide a database for research to enhance knowledge of health, diseases and living conditions in the population living in multi-ethnic areas in northern Norway, with a particular focus on the Sami population. The aims are to prevent ill-health and to improve health services for all.

SAMINOR has been conducted twice before, most recently in 2012-2014, and is administered by the Centre for Sami Health Research at UiT The Arctic University of Norway.

SAMINOR 3 began in the autumn of 2023 and has visited 49 municipalities in central and northern Norway. You were invited when SAMINOR 3 visited your municipality. Even if you could not participate then, we now invite you to answer the questionnaire. The questionnaire provides good information for the health and social care system and for further research.

Why are we inviting you to take part?

We are inviting you to participate because you are between 40 and 79 years old and live in an area where SAMINOR 3 will be conducted. Everyone in this age group, in the whole or parts of your municipality, is being invited. We have found your name and address in the records of the National Population Register, the Norwegian Tax Administration.

Why take part in SAMINOR?

We believe it is important to communicate the results back to participants. As a participant in SAMINOR, you will receive the results of some of your tests if you agree to this. These can provide useful and interesting information about your health.

If you participate, you will make an important contribution to health research. The results of SAMINOR can tell us a great deal about the health situation of the population, which will be useful knowledge for municipalities, county councils, health authorities and the Sami Parliament. They will be able to use this knowledge for preventative efforts that lead to improved health and customized health care services.

What does the study consist of?

Everyone invited to participate in SAMINOR 3 is asked to fill in a questionnaire and receives an invitation to a scheduled physical health examination. The questionnaire includes questions about health, illness and lifestyle and can be completed online or on paper. People aged 70 to 79 years receive the paper questionnaire by post. Paper questionnaires are also available at your physical examination, which will take place either in a bus or in rooms rented in the municipality. You should preferably have completed the questionnaire before your physical examination, but if you have not done so, you may complete it when you come for the examination. If you need help with the questionnaire, the staff at your

examination will assist you. The questionnaire is just as important to research as the physical examination.

What will the questionnaire ask about?

The questionnaire will contain many questions about your health, illnesses and lifestyle, such as:

- cardiovascular diseases and diabetes
- COVID-19
- use of medicines
- physical health problems
- dental and oral health
- use of alternative medicine/traditional healers
- discrimination and harassment
- violence and abuse
- functional impairments
- use of and satisfaction with health care services
- how historical events affect you today
- negative life events
- diet
- quality of life
- mental health
- how human impacts on the climate and natural environment affect you
- work/education/finances
- alcohol and drugs
- social support and coping
- physical activity
- religion
- language, ethnicity and culture

What will the physical examination consist of?

The physical examination will take about 30-45 minutes. We will perform the following measurements and tests:

- height and weight, waist and hip circumference
- heart rhythm (ECG)
- blood pressure and resting heart rate
- grip strength
- lung capacity (spirometry) of selected participants
- some participants will be asked to wear an activity tracker for a week
- blood tests and hair sample
- participants will be asked for a urine sample

Participants over the age of 70 will be invited to take an additional examination, which will take another 30 minutes. This will consist of:

- tests of balance and simple tests of functioning such as sitting down and standing up

- tests of memory and concentration where participants have to recognize words and animals and connect symbols and numbers

What will we analyse in the biological tests?

The blood and urine samples will be analysed to determine:

- blood sugar levels
- blood lipid levels
- haemoglobin levels and iron status
- levels of various enzymes (proteins)
- levels of various salts and minerals
- markers of infection
- various indicators of kidney function
- COVID-19 antibodies (selected participants)
- vitamin B12

The analyses of the samples will be stored in a database with your responses to the questionnaire. The remaining blood samples will be stored in a biobank at UiT The Arctic University of Norway for later use in research.

Feedback on your results

If you are interested, we will give you the results of some of your tests and measurements after your examination. For example, you will receive feedback on your:

- height, weight and body mass index (BMI)
- hip and waist circumference
- blood pressure, resting heart rate
- haemoglobin level
- long-term blood sugar level
- lung capacity (for selected participants)

If any of these results indicate a need for medical attention, you will be advised to see a doctor. You can decide that you do not want to know your results, but if a result shows that you need urgent medical treatment, we will still let you know.

Ongoing information about the study and future research results will be communicated on the SAMINOR website (www.saminor.no), in the press and social media, and at various events and public meetings.

Your privacy, your consent and your rights

Participation in SAMINOR is voluntary. You can take part even if you do not want to be involved in all parts of SAMINOR. As a participant in SAMINOR, you agree that your data and biological samples can be used for research indefinitely. Your consent is valid unless or until you choose to withdraw it. You also agree to be invited to take part in any new or additional surveys.

Your rights

Everyone who has participated in SAMINOR has the right of access to the data recorded about them. You are also entitled to correct any errors in the information recorded about you.

You can withdraw your consent at any time. If you wish to withdraw from the study, you are entitled to have all personal samples and data removed, unless the information has already been included in an analysis, used in a scientific publication or anonymised. If you want to see what information SAMINOR has stored about you or if you wish to withdraw your consent, you can contact us by e-mail at saminor@uit.no.

Contacts

SAMINOR 3 will be conducted by the Centre for Sami Health Research. The Centre will also be responsible for data management, while the data controller of SAMINOR is UiT The Arctic University of Norway. The University has therefore overall responsibility for the storage and availability of the data.

The head of research is the manager of SAMINOR, research professor, dr.med. Ann Ragnhild Broderstad.

The data protection officer of UiT The Arctic University of Norway can be contacted at personvernombud@uit.no

You may also contact the Norwegian Data Protection Authority (*Datatilsynet*) or the Norwegian Health Authority (*Statens helsetilsyn*) if you feel that your data or biological samples have not been processed in accordance with Sections 23-25 of the Health Register Act.

What will happen to your data?

Personal data about you, your responses to the questionnaire, your body measurements and analyses of your biological samples will be stored for future research in a database. UiT The Arctic University of Norway is the data controller. Biological samples will be stored in an approved research biobank at UiT.

All data and samples will be stored without names and national identity numbers. A code will be used to link you to your data and samples; this means that the data are de-identified and that the researchers will not know who you are. The code will be kept separately from your health information and only a limited number of people will have access to the code that could link your data to you.

Your data and samples will be stored indefinitely unless you withdraw your consent.

Who can use data and biological samples from SAMINOR?

In order to gain access to the SAMINOR data, research projects must apply to SAMINOR. Data from SAMINOR may be used in research to improve knowledge about health, diseases and living conditions in the population living in multi-ethnic areas in northern Norway. Research projects using data from SAMINOR must clearly be of benefit to the population in the areas under study.

Any fully qualified researcher (PhD or the equivalent) who is affiliated with a Norwegian research institution can apply for access to SAMINOR data for analysis. Students can also be permitted to use SAMINOR data if their main supervisor is the project manager. The police, insurance companies or other commercial institutions will not have access to the data.

What kinds of data are released?

Researchers will only be given the data necessary for them to answer their specific research questions. Researchers will only have access to de-identified data. This means that information that can identify you has been removed, and the researchers will therefore not know who you are. When the researchers have finished their analysis, they must delete the data they received. Whenever biological material is used, remnants of the samples must be destroyed or returned to SAMINOR.

What are the requirements for access to SAMINOR data?

All research projects that plan to use data or biological material from SAMINOR must comply with Norwegian laws and regulations and have obtained the necessary approvals before the data or biological materials are released.

All health research that includes Sami as a group or collects data from areas where Sami make up a significant proportion of the population, or research on Sami ethnicity, language or culture, requires collective Sami consent. This must be obtained from the Expert Ethics Committee for Sami Health Research of the Sami Parliament for all projects that use information from SAMINOR.

Data may be sent to another country (within or outside the EU/EEA) for use in a research project if the project manager is employed by a Norwegian research institution and if the conditions of the General Data Protection Regulation are fulfilled. Biological samples may also be analysed in laboratories abroad (within or outside the EU/EEA).

Return of results from lab analyses

If research projects use biological material from SAMINOR and conduct analyses of these samples, the results must be returned to SAMINOR. The results of the analyses will then be stored with other SAMINOR data and can be reused.

Possibility of genetic analysis of samples in the future

Genetic analysis may be used in the future to examine genetic markers for disease. This research will only be conducted if the aim is important and useful to the Sami population. Genetic material from SAMINOR will not be used to determine kinship or investigate the origins of the Sami, and will not be shared with the police, insurance companies or other external parties. All samples will be stored without names and ID numbers. A code will link you to your data and samples.

Genetic research will never start until ethical assessments have been conducted and approved by the Expert Ethics Committee for Sami Health Research of the Sami Parliament, the Regional Committee for Medical and Health Research Ethics (REK), and the manager of SAMINOR on the advice of SAMINOR Project Board.

Linking your data to other registers

In some research projects, your data from SAMINOR will be combined with (linked to) data about you in other registers. Researchers who wish to link the data to other registers must obtain advance approval in accordance with Norwegian legislation. Projects are only given permission to link particular data that are necessary to answer specific research questions.

Possible registers are national registers of diseases, income, social security, education, occupation, etc., diagnosis registers in hospitals, or information from other health surveys in which you have participated. Here are some examples:

- The Cancer Registry, the Cause of Death Registry, the Cardiovascular Disease Registry, infection registers, the National Prescribed Drug Registry, the Medical Birth Registry, the Norwegian Patient Registry, the KUHR database (Control and Payment of Health Reimbursements), the FD-trygd social security register, other registers from NAV, registers from Statistics Norway on population, family, social security, education, etc., historical registers and other national registers and censuses.

Links to other registers are made possible by using the 11-digit national ID number of all inhabitants of Norway. This will be done in such a way that researchers cannot identify you. Links to the registers are protected by a code that is stored separately from your data.

Data from the current survey may be combined with data from previous SAMINOR surveys for participants who have taken part in more than one survey.

How to contact us

If you have any questions about SAMINOR or the Centre for Sami Health Research, please contact us at saminor@uit.no. We aim to respond to all queries.

You can also contact us by phone on +47 40 64 94 69. This number will be available during the entire period of data collection.

How to follow the SAMINOR Study

You can read about SAMINOR on our website (www.saminor.no), where you will find updated information about current activity and research results. The reports for the municipalities that participate will also be available on our website. You will also be able to follow SAMINOR on social media.