

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. Your municipality also receives a separate report with group-level results from the municipality.

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.

Every participant is equally important, whether you are Sami, Kven or Norwegian, young or old, healthy or sick. The more people who join, the more holistic and valuable SAMINOR becomes.

What does the study consist of?

Everyone invited to participate in SAMINOR 3 is invited to fill out the questionnaire that is attached with a separate link. The questionnaire has questions about health, illness and lifestyle, among other things, and can only be answered digitally.

The questionnaire

You are invited to fill out our digital questionnaire. The questionnaire is available in Norwegian Bokmål, Southern Sami, Lule Sami, Northern Sami and English.

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

Your privacy, your consent and your rights

Participation in SAMINOR is voluntary. You can answer the questions you feel comfortable with. As a participant in SAMINOR, you agree that your information may be used for research indefinitely. This consent is valid until you choose to withdraw it. You also agree to be invited to new or additional surveys if applicable.

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 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 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 and your responses to the questionnaire will be stored for future research in a database. UiT The Arctic University of Norway is the data controller.

All information is stored without name and personal identification number. A code links you to your information. The code key is kept separate from your health information and only a limited number of people are given access to the code key that can link your information to you. Researchers do not have access to directly personally identifiable information about you. A combined combination of information can in some cases identify a person. SAMINOR places great emphasis on limiting the possibility of being able to identify people indirectly. Researchers are therefore only given limited information that is absolutely necessary for their research purposes.

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

Who can use data from SAMINOR?

If you agree to participate in the study, you agree that your information may be used in research indefinitely. Medical research is constantly changing, and in the future, data may be used in research projects provided that it is in accordance with applicable laws and regulations.

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.

What are the requirements for access to SAMINOR data?

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

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.