



NORSPIS

Norsk kvalitetsregister for
behandling av spiseforstyrrelser

To parents/guardians of patients under 16 years of age

Important information about the Norwegian Quality Registry for Treatment of Eating Disorders (NORSPIS)

This letter provides information about the Norwegian Quality Registry for Treatment of Eating Disorders (NORSPIS). Please take the time to read the letter thoroughly, and talk to your child about the information stated here. Contact your child's therapist in the Specialised Health Services or NORSPIS if you have any questions.

Why am I receiving this letter?

You have received this information letter because **your child is under the age of 16** and is being assessed or treated for an eating disorder in the Specialised Health Services. NORSPIS collects information about all patients to whom this applies. In the letter you will find information about how NORSPIS processes and uses the information about your child, what rights you have, and how you can make use of these rights.

What do I need to do?

You do not have to take any action if you accept that your child's information is stored and used in the manner described in this letter. If you do not want your child's information to be stored and used in NORSPIS, you must reserve your child against such use (see below).

What is NORSPIS?

NORSPIS is a national medical quality registry, which collects information on all patients who receive assessment or treatment for an eating disorder in the Norwegian Specialised Health Services. The purpose of NORSPIS is to: 1) gain more knowledge about eating disorders and their treatment, 2) improve the treatment services provided. Another secondary purpose of NORSPIS is to contribute to research on eating disorders. Nordland Hospital Trust is responsible for the registry, and ensures that personal and health information in the registry is processed in a safe manner, so that we safeguard privacy and confidentiality. The Personal Health Data Filing System Act and the Regulations concerning Medical Quality Registries regulate how NORSPIS is run.

What information is collected and stored in NORSPIS, and where is it obtained from?

The registry collects your child's name and national identity number, and answers to questionnaires from patients and therapists at the start and end of treatment. It is standard to ask the patient, or parent/guardian, to complete questionnaires as part of the assessment in the Specialised Health Services. The questionnaires are about your child's ailments, and functioning in everyday life. Your child, or you on behalf of your child, is also asked to respond to questions about your experiences with and benefits from the treatment. If your child has turned 16 when the treatment is finished, NORSPIS will also send out questionnaires one year later.

The therapist/treatment provider answers questions about the type of eating disorder, other diseases, the type of treatment that has been given, and some medical questions about weight and height, among other things. It may be necessary for the therapist/treatment provider to read your child's patient records to check that the treatment information they register in NORSPIS is correct. NORSPIS may also collect this and similar information from the Norwegian Patient Registry (NPR).

Names and national identity numbers are collected to link this information to personal identity. This is to ensure that the registrations in NORSPIS are correct, that we can follow the patient over time if treatment is received in several places, and that it should be possible to compare data in NORSPIS with other registries. Only persons with access to the registry can see who the information relates to. Everyone with access to the registry has a duty of confidentiality. The information is stored permanently in the registry, or as long as is necessary to fulfil NORSPIS's purposes.

How is the information in NORSPIS used?

The information in NORSPIS may only be used as stipulated in the purpose and regulations applicable to NORSPIS. The information in NORSPIS is used to make reports and statistics. It is possible to apply for information from NORSPIS to use in quality or research projects, including across institutions (for example at different hospitals).

Projects must have approval from the appropriate agencies, where required. The information is normally provided without name, national identity number or other directly recognisable information, by means of a code that links the patient to his/her information. There may be separate invitations to provide additional information for e.g. research projects, but you can refrain from this on behalf of your child. Personal data from NORSPIS may be combined (compiled) with information in other registries. All published results and statistics that use information from NORSPIS will be anonymous, so it will not be possible to identify any individual patient.

Your parent/guardian rights

You have the right to decide that your child should not participate in NORSPIS. Then you need to reserve your child. You can do this at any time, without giving a reason. This will not affect the treatment your child receives now or in the future. If you reserve your child, the information in NORSPIS will be deleted. You can ask to see the data stored and to correct any information that is incorrect. You can ask to know who has had access to or been provided with health information about your child. You can get help from the Data Protection Officer at Nordland Hospital. If you believe that your child's information is processed incorrectly, you can send a complaint to the Norwegian Data Protection Authority or the Norwegian Board of Health Supervision.

How to reserve your child

1. You can either: Reserve your child online, via Helsenorge. Log in to www.helsenorge.no and select that you represent your child. Tap your child's name -> Profile & Settings -> Privacy settings. Click on the button "Change settings" under "Research, screening and health registries". Select "Norsk kvalitetsregister for behandling av spiseforstyrrelser (NORSPIS)", then click on "Reservasjon mot lagring av personopplysninger i NORSPIS" (which means "Reservation against storage of personal data in NORSPIS"). Tick off here, then click on "I wish to opt out" and then "Create opt-out".
2. Or: Contact NORSPIS, and we will create the opt-out for you. You will receive a written confirmation that you have reserved your child.

More information

On our website norspis.no you will find:

- An overview of all the questionnaires collected by NORSPIS.
- Regularly updated information on how data from the registry is being used.

Contact information for NORSPIS

- Phone: 75501081
- E-mail: norspis@nlsh.no (please do not send any sensitive information via e-mail)
- Mailing address: NORSPIS, Nordland Hospital Trust, Regional Centre for Eating Disorders, Postboks 1480, 8092 Bodø

Contact information for the Data Protection Officer at Nordland Hospital Trust

- Phone: 75571927
- E-mail: personvernombudet@nordlandssykehuset.no (please do not send any sensitive information via e-mail)
- For more information about the Data Protection Officer: www.nlsh.no

Contact information for the Norwegian Data Protection Authority

- Phone: 22396900
- Mailing address: Data Protection Authority, Postboks 458 Sentrum, 0105 Oslo
- For more information about complaints and your privacy rights: www.datatilsynet.no/en

Contact information for the Norwegian Board of Health Supervision

- Phone: 21529900
- Mailing address: Norwegian Board of Health Supervision, Postboks 231 Skøyen, 0213 Oslo
- For more information: www.helsetilsynet.no/en

Thanks to everyone who contributes to NORSPIS!