

## NORGAST – The Norwegian Register for Gastrointestinal Surgery

### **Information about data registration in the Norwegian Register for Gastrointestinal Surgery (NORGAST) and your right to opt out**

#### **Background and purpose**

Norwegian healthcare professionals have established the Norwegian Register for Gastrointestinal Surgery – NORGAST. The objectives of the register are to monitor, ensure, and improve the quality of treatment for all patients undergoing surgery on abdominal organs, the esophagus, or abdominal wall.

The University Hospital of Northern Norway (UNN) is responsible for the register, represented by its CEO. The register is legally based on the General Data Protection Regulation (GDPR), Articles 6(1)(e) and 9(2)(j), as well as Norwegian regulations on medical quality registries.

#### **What information is collected?**

The register includes your name and personal ID number, details of your abdominal surgery, your recovery, and any complications. No extra tests, interventions or examinations will be performed.

#### **Where does the information recorded in the registry come from?**

Your doctors and nurses record information from your electronic patient journal regarding the treatment you receive during your hospital stay and at discharge from the hospital. This data is transferred manually from your hospital records to the national register, where it is stored in an anonymized form. Additional information may be collected from other healthcare institutions, your GP, or national registers such as the Norwegian Patient Registry and the National Population Register.

#### **Who has access to the data?**

All information is treated confidentially. Only staff working with the register can access the data, and strict confidentiality rules bind them.

#### **Research and quality improvement**

To ensure and improve the quality of healthcare services, it is necessary to use scientific research methods to analyze the data collected in the register. Researchers may, for example, use the register to study which factors are associated with good or poor treatment outcomes, or to evaluate how different treatments affect patients in terms of social, medical, and health-economic aspects.

For specific research projects, it may also be relevant to link information from NORGAST with data from other national health or population registers (see the list provided). Any such data linkage requires prior approval from the relevant public authorities, as required by law.

Because hospitals across Norway record the same type of information in NORGAST, it is possible to compare results nationwide. This allows both benchmarking for quality assurance and research into the long-term consequences of surgical treatment.

Importantly, all results from analyses will be presented at an aggregate level and will never be traceable back to individual patients. Any research projects that go beyond quality improvement must be reviewed and approved by the Regional Committee for Medical and Health Research Ethics (REK).

#### **Your rights**

Your data will be stored only as long as necessary to meet the register's goals, in line with GDPR and Norwegian law. All information is kept strictly confidential. You do not need to do anything unless you want to opt out. If you choose to opt out, all data about you will be deleted. This will not affect your future treatment or follow-up. Information from past (or future) operations will also be deleted.

More details about the register and your rights can be found at [www.norgast.no](http://www.norgast.no) and [www.kvalitetsregistre.no](http://www.kvalitetsregistre.no)

If you believe your data is not being handled correctly, you can contact the Data Protection Authority (Datatilsynet) or the Norwegian Board of Health Supervision (Statens Helsetilsyn).

**How to opt out**

You can opt out by logging in at [www.helsenorge.no](http://www.helsenorge.no). More information and instructions are available at [www.norgast.no](http://www.norgast.no). You can also contact the Register directly by phone (+47 777 54 287) or email ([norgast@unn.no](mailto:norgast@unn.no)). For privacy reasons, we will follow up by phone to confirm your personal ID number if you email us. All your data will be deleted from the NORGAST Register if you opt out.

**Linking with other registers**

Each year, NORGAST data is compared with the Norwegian Patient Registry to measure completeness. Data may also be linked with other registers and population studies, such as:

The Medical Birth Registry of Norway (MBRN)  
The Norwegian Patient Registry (NPR)  
The Cancer Registry of Norway (CRN)  
The Norwegian Prescription Database (NorPD)  
Statistics Norway's Events Database (FD-Trygd)  
Cohort of Norway (CONOR)  
The Norwegian Intensive Care and Pandemic Registry (NIPaR)  
Population surveys from the National Health Screening Service (SHUS)  
Tax Administration Databases  
The Norwegian Cardiovascular Disease Registry (HKR)  
National Population Register  
The Norwegian Cause of Death Registry  
The Norwegian Registry of Primary Health Care (KPR)

In some cases, information from your medical records may also be used.

All such linkages require prior approval from the relevant authorities, such as the Data Protection Officer, the Regional Ethics Committee, and the Data Protection Authority.

All information in the registry is handled with full respect for your privacy and in line with Norwegian laws and regulations.

**Contact information**

The senior doctor responsible for your treatment at \_\_\_\_\_ Hospital is \_\_\_\_\_ Tel.: \_\_\_\_\_.

The Data Protection Officer (DPO) at the hospital is \_\_\_\_\_ Tel. \_\_\_\_\_.

Best regards,

The NORGAST management team

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