

Information to people with diabetes about the Norwegian Adult Diabetes Register.

The aims of the register

The Norwegian Adult Diabetes Register is a national quality register. The primary aim of the Register is to improve the quality of the treatment of people with diabetes. The Register also provides data for research on diabetes and diabetes related conditions. Helse Bergen HF, Haukeland universitetssykehus, is responsible for the management of the Register's data (data controller function). Noklus who are located Haraldsplass Diakonale Sykehus are responsible for the day-to-day running of the Register. Helse Bergen HF have to ensure that your health-related personal data are processed in accordance with Europe's new framework for data protection laws (the General Data Protection Regulation, GDPR) and the Norwegian Health Register Law.

What the register will record about you:

- General information: Name, social security number, address, gender and name of your General Practitioner. The National Registry will be used to check information.
- Health information: Type of diabetes, year of diagnosis, referral to diabetes specialist, results of annual diabetes check-up including retina examination, diabetes-related complications, height, weight, smoking habits, exercise habits, self-monitoring of blood sugar, results of laboratory examinations, prescribed medicines for diabetes and heart disease, together with diabetes education and devices used for insulin delivery and glucose monitoring.
- Patient reported outcome measures: Information about quality of life and different aspects or challenges associated with living with diabetes.

It is also possible that you may be asked to consent to provide an extra blood or urine sample, for example when you consult your doctor. These samples will be stored frozen in the Bergen Health Trust Bio-bank (a bio-bank that the Register has a collaboration agreement with). The samples will only be used for diabetes related research. Bio-bank samples will only be collected if you agree to sign a separate written consent form.

Your diabetes doctor will transfer information regularly from your Electronic Health Record to the Norwegian Adult Diabetes Register. Alternatively you may supply information about your diabetes or diabetes management directly to the Register. Personal data about your diabetes will always be transferred using secure data technology that is protected against unauthorized access.

Linkage with data from other sources:

It may be necessary to obtain diabetes-related information from other national registers either for research purposes, or to check that information about you is correct and complete. A notification will appear on our home site (www.noklus.no) each time such a linkage is performed. Examples of registers where data linkage might be considered necessary are: the Children's Diabetes Register,

the Prescription Register, the Kidney Register, the Cardiovascular Register, the Medical Birth Register, the Cancer Register, the Register of Deaths, the Education Register, the Sick Leave Register and the Norwegian Patient Register (includes information about all patients that are treated at hospitals or by practicing specialists) .

Personal health-data will not be used for research purposes unless the study has been approved by the appropriate Research Ethics Committee, the data protection officer at the research institution or the Norwegian Data Protection Authority.

Personal health-data is kept as long as it is necessary to fulfill the aims of the Norwegian Adult Diabetes Register. Your information will always be stored securely and all staff who work with information held in the Register are bound by strict confidentiality laws. Helse Bergen HF (as data controller) will ensure compliance with current data protection legislation.

Your rights to object

You have a right to object to your information being stored in the Norwegian Adult Diabetes Register. If you register an objection with us, we will delete information about you from the Register with the exception of data that has already been used in health analyses or scientific publications. Your doctor is aware of your rights and it will not affect your relationship with your doctor if you decide to opt out of the Register now, or at a later date. You are also entitled to read the information the Norwegian Adult Diabetes Register holds on you. If you think that any information in the register is wrong, you can contact us. If the information is wrong, we will correct it.

You can utilize your rights by contacting us at Noklus t: 55979500

Sharing of information from the Norwegian Adult Diabetes Register only occurs in accordance with the aims of the Register. Your name and social security number will be replaced by a linkage key when personal information is shared with a partner organisation.

Contact information

More information about the Norwegian Diabetes Register for Adults can be obtained by contacting Noklus, t: 55 97 95 00. You can also find information about the Register at: www.noklus.no

Helse Bergen HF has a data protection officer whose duties are to ensure that personal health-related data is processed in accordance with applicable data protection laws, and that your rights concerning the protection of personal data are taken into account. If you have any questions about your rights concerning personal data, you can contact our data protection officer t: 55975558 or email: personvernombudet@helse-bergen.no

If you mean that your rights concerning the protection of personal data have been violated, you may contact the Norwegian Data Protection Authority (Datatilsynet) or the Norwegian Board of Health Supervision (Helsetilsynet).