

Complete patient information

What is Q-IVF?

Since 2007, the IVF clinics in Sweden, with the support of SKR (Swedish Association of Local Authorities and Regions), have run a national quality register for assisted reproduction, Q-IVF. The purpose of the register is to continuously monitor treatment results and any medical risks for both IVF children and the treated patients.

You contribute to better care!

To develop and ensure the quality of assisted reproduction, your clinic wants to report information about your treatment(s) to Q-IVF. Participation in the register is voluntary and does not affect the treatment you receive. The data is used to compare care between different clinics around the country. The results are also used for improvement work at the clinics. The quality register contributes to new knowledge about how we should treat involuntary childlessness and the more people who participate, the statistically more reliable the results will be.

Data recorded

To develop and ensure the quality of IVF care, your clinic registers details of your social security number and treatment.

Results are compiled annually and the clinic receives statistics on its own results via the register. A national compilation is also made of data from all IVF clinics in Sweden. It is not possible to identify and trace individuals in the compiled material.

Controllers of personal data

The central data controller for Q-IVF is Karolinska University Hospital in Stockholm. Your clinic is the data controller for the processing in connection with the collection and transfer of data about you to Q-IVF.

Confidentiality

Your information is covered by confidentiality (Public Access to Information and Secrecy Act). This means that information may only be disclosed from the register if it is clear that neither you nor anyone close to you will suffer harm if the information is disclosed. The data has the same strong protection as medical records.

Your privacy is further protected by the fact that data from the register may only be disclosed for research, quality assurance and statistical purposes. Even if the disclosure is made for any of these purposes, a confidentiality assessment takes place. Before information from the register is subject to a research study, approval by the ethical review authority is always required.

A "Number calculation for clinical research" may also occur, which means a calculation that is made, at the request of researchers, of how many people meet certain pre-established criteria and who may thus be included in the research.

Security and access

Some of the staff at the clinics that submit information to the register have electronic access to data from their own clinic as well as national data. A few specially appointed staff who work with the register centrally also have access to information about individual patients.

Those who have electronic access to the data must log in to the register with secure two-step authentication. The security system around the servers where data is stored meets the same rigorous requirements as for the medical records. All staff have a statutory duty of confidentiality.

Storage time

Following a decision by the archive authority at Karolinska University Hospital, your data is stored until further notice to be used for historical, statistical or scientific purposes.

Your rights

- You have the right to refrain from being registered in the register, participation is voluntary. If you do not want to participate, you must notify your clinic. It is possible to do this verbally, but for security and traceability, we prefer that you fill out a "No form" that you can get at your clinic. It is also available for download on Q-IVF's website (under "For patients"). If you wish to have previously reported data deleted at the register, this must be done in writing.
- You have the right to have inaccurate personal data corrected and to complete incomplete personal data.
- You are entitled to compensation if the personal data is processed in violation of the General Data Protection Regulation or the Patient Data Act.
- You have the right to lodge a complaint with the supervisory authority the Swedish Authority for Privacy Protection's.

Contact

- If you want to request correction, contact the clinic you have been treated at.
- For information about the access to your data, please contact the registry coordinator, see www.qivf.se for contact details.
- If you have any comments on how your personal data has been processed, please contact:
dataskyddsbud.karolinska@regionstockholm.se

Mer information

On Q-IVF's website www.qivf.se you will find contact information for the registry as well as annual reports with treatment results, patient perceived quality, open comparisons, etc.

You can read more about quality registers on www.kvalitetsregister.se and on the Swedish Authority for Privacy Protection's website, www.imy.se

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