

Information for parents whose newborn infant has been admitted to a neonatal unit

Swedish neonatal care is among the best in the world, but care and results can still be improved. The Swedish Neonatal Quality Register (SNQ) is a national quality register for newborn care. The goal of SNQ is to develop and secure the quality of care.

All neonatal departments in Sweden have chosen to report data on admitted infants to SNQ. Basic information about pregnancy and childbirth, as well as the condition, treatment, and diagnoses of your infant will be transferred to SNQ. For infants who have needed more comprehensive care, information from follow-up visits is also reported.

You contribute to a better care

By participating in SNQ, your child contributes to an improvement of neonatal care. The more people who participate in data collection, the safer and more effective the care will be. The information in SNQ is used for quality improvement and, with the help of data in the register, we are given unique opportunities to evaluate which methods and treatments, medicines and products result in a good outcome for your child. Participation is voluntary.

How data is handled

Data is collected from your child's patient record and from you as a parent and guardian. Some information from the maternal birth record is also included. For SNQ to get your opinion about how neonatal care and nursing work, you may be asked to complete a specific survey. SNQ data may only be used to develop and secure the quality of care, to produce statistics and for research in the healthcare sector. Data may, after confidentiality testing, be disclosed to a person intending to use the data for one of these three purposes.

Data from SNQ can be transferred electronically. When SNQ data will be used for research, the approval of an Ethical Review Board (Etikprövningsnämnd) is always required.

Secrecy

The information about your child is protected by the Swedish Public Access to Information and Secrecy Act. As a rule, this means that information about your child may only be released from SNQ if it is clear that neither your child nor any related person will suffer. Data used for research will be anonymised, and only compiled data will be publicly displayed.

Security

Your child's record is protected against unauthorized persons. There are special requirements meaning, among other things, that only those in need of the data can reach it, and a control procedure ascertaining that no unauthorized person has had access to it. Data is protected by encryption and there is a safe logon procedure to access it.

Access

Your child's healthcare provider can retrieve the information they have previously provided to SNQ. No other healthcare provider has access to this data. Those who centrally manage SNQ can and may access your child's record.

Sorting out data

The information about your child will be removed from the register when it is no longer needed to develop and secure the quality of care.

The rights of your child

- Your child's participation in SNQ is voluntary and does not affect the care he or she receives. If you do not want your child's data to be registered, please contact the physician in charge.
- You have at any time the right to have your child's record deleted from SNQ.
- You can get information about which care provider has accessed your child's record and at what time this has happened.
- You may be entitled to reimbursement and may request a correction if your child's record is handled in violation of the European General Data Protection Regulation (GDPR).
- You have once a year, free of charge, the right to know what information has been registered about your child. If so, a written and personally signed application for a register extract should be sent to one of the SNQ contact persons listed on the home page at www.snq.se.

Data controller

Each quality register has a data controller, usually a county council rather than a physical person. For SNQ, Västerbotten County Council has this responsibility. If you need additional information, please contact your child's doctor or read more at www.snq.se.

For the Swedish Neonatal Quality Register

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