

QUALITY REGISTER - SWEDISH CHILDHOOD CANCER REGISTER

INFORMATION ABOUT SWEDISH CHILDHOOD CANCER REGISTER FOR PATIENTS >18 YEARS/GUARDIAN(S)

Your healthcare provider

is one of six pediatric oncology centers in Sweden investigating and treating children and young people for blood and tumor diseases. In addition to healthcare and teaching, the unit also conducts extensive research and development work. Most of the advances in healthcare have been achieved through such work. Since blood and tumor diseases are rare in children, they are often treated in a uniform manner. This means that patients follow a common treatment program or treatment protocol. To evaluate these protocols, data about the child's disease and treatment are recorded in a register.

In order to develop and ensure the quality of care, Your healthcare provider

would like to report information about you/your child to the National Quality Register - the Swedish Childhood Cancer Register. The Central Personal Data Control Authority is Karolinska University Hospital, which has overall legal responsibility for the personal data in the Swedish Childhood Cancer Register. Your healthcare provider

is the data controller in charge of processing when data is collected and disclosed to the Swedish Childhood Cancer Register.

YOU ARE CONTRIBUTING TO BETTER HEALTHCARE

Via research, continuous evaluation and critical examination of treatment, we will be able to continue to improve treatment outcomes and reduce the risk of side effects. In order to arrive at safe conclusions, we need to gather experiences from large groups of patients, sometimes from several different countries, who have been treated in a similar fashion. Often, the treatment protocols we use are also research studies. This means that there is already a proven treatment, but that a research center in Sweden or abroad has taken responsibility for trying to improve treatment in some way. In these cases, the treatment is determined by the study center and you choose whether or not you/your child will participate in the study. The aim of all projects is to understand and prevent the onset of disease and complications and/or to develop the form of treatment.

All research projects require the approval of the Ethics Review Board.

By being included in the Swedish Childhood Cancer Register, you/your child are contributing to improving healthcare. Participation in the register is voluntary and does not affect the care you/your child will receive. The data are used to compare healthcare offerings between different hospitals and healthcare providers around the country. We will then use the results in our improvement work. The Quality Register contributes to new knowledge about how to treat blood and tumor diseases and the more people who participate, statistically the safer the results are.

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DATA RECORDED

In order to develop and ensure the quality of healthcare, we would like to record such information as your child's social security number, gender, medical history, healthcare contacts, diagnosis, treatment, test results, radiological examinations, the disease characteristics and subsequent state of health.

The data are forwarded to the Swedish Childhood Cancer Register and possibly other study centers, sometimes abroad, that analyze and use the data for statistical processing. Only information necessary for processing is disclosed. For example, only the social security number is used to identify patients in Swedish healthcare, census and health data registers. For all other types of use, code numbers are used for identification. Follow-up often takes place during a long period of time and consequently obtain data from the medical records of the clinics that may take over follow-up procedures after the Children's Clinic for Quality Assurance and Statistical Compilations.

The results of the statistical analyses are used to see whether the treatment works and to find new ways to improve it. The results of the analyses may be published in scientific journals in order to benefit more children/young people. The results published are completely anonymous and individual patients cannot be identified.

LEGAL BASIS

Anyone processing personal data must have a legal basis to do so. Your healthcare provider

and Karolinska University Hospital may collect and register data in the Swedish Childhood Cancer Register because it is considered to be necessary information that is of general interest to the community (Article 6.1 e). We may also process health data in the register because it is necessary for reasons associated with providing healthcare (Article 9.2 h). Our staff, as well as the staff at Karolinska University Hospital are also subject to a statutory duty of confidentiality (Article 9.3). According to the Data Protection Regulation, there should also be legal support in Swedish law when processing personal data in quality registers. Such provisions can be found in Chapter 7 of the Patient Data Act (2008:355).

THIS IS HOW YOUR DATA IS HANDLED

Information about you/your child is collected from the medical records, from you/your child himself/herself and from

. Your/your child's data in the Quality Register may only be used to develop and ensure the quality of care, produce statistics and for research in the healthcare sector. After a confidentiality assessment, the information may also be disclosed to someone who will use the data for any of these three purposes. Any information that the Swedish Childhood Cancer Register can disclose may be done electronically.

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CONFIDENTIALITY

Your/Your child's data in the Quality Register is protected by medical confidentiality of the Public Access to Information and Secrecy Act (2009:400). As a general rule, this means that the Swedish Childhood Cancer Register may only disclose information if it is clear that neither you/your child nor any loved one suffers any inconvenience but if the information is disclosed.

SECURITY

Your/your child's information in the Swedish Childhood Cancer Register is protected against access by unauthorized persons. There are specific security measure requirements, implying, among other things, that only those persons who need your/your child's data may have access to them, that there should be verification that no unauthorized person has access to this information, that the data should be protected through encryption and that there should be a secure way of logging on to access data.

ACCESS

As reporting healthcare providers, authorized staff of your healthcare provider

have direct access to the information reported to the Swedish Childhood Cancer Register, but if you/your child has another home county council, even people responsible for care in your home county council will have direct access as well as those individuals who have the task of checking the quality of the register. No third-party health care facility has direct access to this information. As a result of their responsibility for the register, qualified staff at Karolinska University Hospital may also have access to information about you/your child.

STORAGE TIME AND SCREENING

Your/Your child's information in the Swedish Childhood Cancer Register can be removed after a decision by the archival authority in your county council. However, an important purpose of the Swedish Childhood Cancer Register is to track the long-term effects of childhood cancer and treatment later in life, involving very long-term data storage. Thus, normally the data will be saved until further notice to be used for historical, statistical or scientific purposes.

YOUR RIGHTS

- You have the right to refuse having your/your child's personal data recorded in the Swedish Childhood Cancer Register.
- At any time, you also have the right to have information about you/your child deleted in the register.
- You have the right to receive confirmation on whether personal data relating to you/ your child is being processed by Karolinska University Hospital and if so

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receive a copy of your personal data free of charge. You also have the right to receive personal data in electronic format.

- You have the right to get incorrectly entered personal information about you/your child corrected and to supplement incomplete personal data.
- You have the right to request that processing of your/your child's data to be restricted if
 - you deem that your personal data is not accurate and for a period of time that allows Karolinska University Hospital to check if your personal information is correct.
 - you feel that the processing is illegal and oppose the deletion of personal information and instead request a restriction in its use.
 - in a situation where Karolinska University Hospital no longer needs the personal information for processing purposes (see above), but you believe that you will need it to be able to establish, exercise or defend legal claims.
- You have the right to receive notification about which healthcare unit and at what point in time someone has had access to your/your child's data.
- You/your child is entitled to damages if personal data is processed in violation of the Data Protection Regulation or Patient Data Act.
- You have the right to lodge a complaint with the supervisory authority.

CONTACT INFORMATION

If you would like more information about the Swedish Childhood Cancer Registry, have access your/your child's data, request a correction, restriction, deletion, or would like to obtain information about what data has been accessed, please contact:

National Quality Register – Swedish Childhood Cancer Register, Karolinska Institutet, Cancer Research Unit, Tomtebodavägen 18A, 8th floor, 17177 Stockholm (Solna)

Phone: +46 8 52482365

Email: svenska-barncancerregistret@kbh.ki.se

If you would like to contact the Data Protection Officer at

or at Karolinska University Hospital:

Data Protection Officer
Karolinska University Hospital
SE-17176 Stockholm
Phone: 08-517 700 00 (switchboard)
E-mail: dataskyddsbud.karolinska@sll.se

You can also read more about the Quality Register at www.kvalitetsregister.se

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If you believe that the information is insufficient or unclear, we advise you to speak to the physician in charge. It is important to ask questions about anything is unclear.

The patient/guardian will receive a copy of this information.