

QUALITY REGISTER - SWEDISH CHILDHOOD CANCER REGISTER

INFORMATION REGARDING CONTINUED REPORTING OF DATA TO THE SWEDISH CHILDHOOD CANCER REGISTRY

This information is directed to those who have been treated/are being treated for a disease registered in the Swedish Childhood Cancer Register. In connection with the onset of your disease, your guardians were informed of this. Now that you are of legal age, we would like to provide you with updated information about what has been reported in the register.

If you accept that the information we have about you in the Swedish Childhood Cancer Register should remain there, you do not need to do anything at all.

If you would like to know more about the purpose of the Swedish Childhood Cancer Register, please read information we have gathered below.

BACKGROUND

In addition to health and education, the six pediatric oncology centers in Sweden are carrying out extensive research and development work. As part of this work, information about your disease and the treatment you have received has been registered in the Swedish Childhood Cancer Register.

In order to evaluate the treatment in the long term, we are keen to continue monitoring your status via this register. We are doing this in order to register the complications of your disease and administered treatment that can arise at times.

Thus, we would also like to retrieve data from your medical records at those clinics that may very well take over the monitoring of your disease status.

To learn more about late complications, we would also like to have the opportunity to cross-checking data from follow-up work with other registers, such as the patient register. We may contact you again if we discover something that might be of importance for your health.

Compilations of analysis results from the register do not contain data that allows an individual to be identified. Under the General Data Protection Regulation, your data will always be treated according to the confidentiality requirements imposed by law. .

You may at any time refuse further registration, request transcripts from registers or request that data in the register be deleted or register statements or ask that the data in the register be deleted or anonymized.

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 personal data

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controller for handling when the data was collected and disclosed to the Swedish Childhood Cancer Register.

YOU ARE CONTRIBUTING TO BETTER HEALTHCARE

You are helping to improve healthcare by being in the Swedish Childhood Cancer Register. Participation in the register is voluntary and will not affect the healthcare care you are receiving/have received. 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 on how to treat blood and tumor diseases and the more people who participate, the statistically more reliable the results are.

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 Swedish Data Protection Regulation, the processing of personal data in quality registers must also have legal support in Swedish law. 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 is collected from your medical records, from you personally and from

Your data in the quality register may only be used to develop and secure quality of care, produce statistics and for research within 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.

CONFIDENTIALITY

Your information 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 the Swedish Childhood Cancer Register may only disclose information about you if it is clear that neither you nor any person related to you will suffer if the information is disclosed.

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SECURITY

Your information in the Swedish Childhood Cancer Register is protected against access by unauthorized persons. There are specific requirements for security measures involving, among other things, that only those who have a need of your information may have access to it, that there is verification that no unauthorized party has had access your information, that your information is protected through encryption and that login to access information may only carried out in a safe manner

ACCESS

In their capacity as reporting healthcare providers the qualified staff of

have direct access to the information reported to the Swedish Childhood Cancer Register, but if you are a resident of another county council, even those responsible for your healthcare in your home county council have direct access as well as the persons with the task of checking the quality of the register. No third party healthcare facility has direct access to this information. As persons responsible for the register, qualified staff at Karolinska University Hospital also have access to information about you.

STORAGE TIME AND SCREENING

Your 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 personal data recorded in the Swedish Childhood Cancer Register.
- You have the right to have information about you in the register deleted at any time.
- You have the right to confirm whether personal data relating to you is being processed by Karolinska University Hospital and if so, 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 have incorrect personal information corrected and to supplement incomplete personal data.
- You have the right to request that the processing of your data be limited 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.

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- in a situation where Karolinska University Hospital no longer needs 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 obtain information about which healthcare unit and at what time someone accessed your information.
- You are entitled to damages if the handling of personal information is in breach of the Data Protection Regulation or the Patient Data Act.
- You have the right to lodge a complaint with the supervisory authority

If you accept that the information we have about you in the Swedish Childhood Cancer Register should remain there, you do not need to do anything at all.

CONTACT INFORMATION

If you want more information about the Swedish Childhood Cancer Registry, please access your data, request a correction, restriction, deletion, or if you would like information about any access granted to your data, please contact:

National Quality Register – Swedish Childhood Cancer Register, Karolinska Institutet, Childhood Cancer Research Unit,

Tomtebodavägen 18A, 8th floor, SE-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 would like to contact the Swedish Childhood Cancer Register, please send this counterfoil to the address found on the previous page.

I would like (if desired, check off one or more of the following):

- ☐ extracts from the Swedish Childhood Cancer Register
- ☐ to have my data in the Swedish Childhood Cancer Register anonymized
- ☐ to have my data in the Swedish Childhood Cancer Register deleted
- ☐ more information about the Swedish Childhood Cancer Register

My contact details:

Name:

Address:

Phone number:

Date / Name / Signature