

## QUALITY REGISTER - SWEDISH CHILDHOOD CANCER REGISTER

### INFORMATION ABOUT THE SWEDISH CHILDHOOD CANCER REGISTER FOR CHILDREN AND YOUNG PEOPLE UNDER THE AGE OF 18

Cancer and hereditary diseases (e.g. blood diseases) are rare in children. However, the very fact that the diseases are rare makes it a little harder for we who work in the healthcare sector to find new and effective ways to treat and cure those children who still get sick. We try to find the best treatment by treating lots of children in the same way, and then by looking at the results and comparing these with how things were before, or with another group of children receiving a different kind of treatment. In order for such a comparison to be as satisfactory as possible, we must collect information about each child in a register. By compiling and analyzing this information, we are thus able to understand how to improve treatment so that more children can become healthy.

In order to develop and ensure quality in healthcare, your healthcare provider

will report information about you 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

Using the information in the registers and saved samples, we hope to be able to further improve treatment outcomes while simultaneously reducing the risk of side effects. In order to arrive at firm conclusions, we need to gather information from a sufficiently large number of children and young people. As the diseases are rare, we sometimes need to work with doctors in several countries in order to obtain information about a sufficiently large number of children. Agreement is reached on a common treatment protocol based on all existing knowledge.

In order to compare results with previously treated patients, information related to the patient, the disease and its treatment is collected. This information is saved in a register located on one of the countries cooperating in the protocol. The patient must always be informed of such registration. Sometimes patients must also give their permission to save data in such records. In the future, we would also like to register information from those clinics taking care of your health if you have stopped going to the Children's Clinic.

Participation in the Swedish Childhood Cancer Register is voluntary and does not affect the care you are receiving.

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## DATA RECORDED

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

The information will be forwarded to the Swedish Childhood Cancer Register, and perhaps to the study center responsible for the treatment protocol used (this study center may be located in another country).

## CONFIDENTIALITY AND SECURITY

Information in the Swedish Childhood Cancer Register is protected by professional secrecy laws. This means that no information may be disclosed if there is a risk that it will cause you harm. There are specific security measure requirements to ensure that no one else may gain access to your information. There should be checks and safeguards to prevent any outside third party from becoming privy to your information. Your data is protected through encryption and a login is required to read the information.

## ACCESS

In some cases, the responsible pediatrician in your home county council and the persons tasked with checking the quality of the registry may have direct access. No third party healthcare facility has direct access to this information.

Your information will remain in the register as long as it is still needed for research and development. Research reports and other compilations will not contain information that allows you or other patients to be identified.

- You have the right to refuse to have your personal data registered in the Swedish Childhood Cancer Register.
- You have the right to have your information in the register deleted at any time.
- You have the right to receive information about what has been registered about you.
- If any part of the information about you is inaccurate, you have the right to have it corrected.
- You have the right to receive information about which healthcare unit/person has seen your information.
- You are entitled to compensation (damages) if the regulations pertaining to confidentiality have not been complied with.

## CONTACT INFORMATION

If you would like more information about the Swedish Childhood Cancer Register or about the data registered about you, please contact:

## QUALITY REGISTER - SWEDISH CHILDHOOD CANCER REGISTER

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

If you feel you have not received enough information, it would be a good idea for you to talk to the physician in charge. It's important to ask questions about anything that is unclear.

*The patient has been given a copy of this information.*