

Information about the registration of cancer for patients under 20 years of age and their legal representatives

Since January 2020 there has been a legal requirement for specific data about cancer to be registered throughout Switzerland.

As a patient or the legal representative of a patient (e.g. parents), you have the right to be informed about cancer registration and to object to this if you wish. You also have the right to receive information about data that have been registered.

Is there a legal basis for cancer registration?

Yes, the Federal Act on the Registration of Cancerous Diseases (CRA; SR 818.33 – in force from January 2020). This Act regulates the recording of informative and reliable data about cancer in Switzerland.

Who will provide me or my child with information?

The doctor who tells you the diagnosis is responsible for providing you (or your child) with information. This may be the doctor treating your child. But the doctor treating your child may also request a medical professional to inform you.

What information will I or my child be given?

You (or your child) will be informed about the rights you (or your child) have in relation to the Cancer Registration Act, about protection of your (or your child's) personal data and about the reasons why cancer is registered.

How will information be given to me or my child?

You (or your child) will be informed verbally and will be given a patient information brochure.

Why is national cancer registration done?

The aim of registering cancer, regulated by law from January 2020, is to standardise the way information about cancer is recorded. This will improve the quality of the data available about childhood cancer in Switzerland. Informative, reliable data are needed so that the development of childhood cancer can be observed over many years throughout Switzerland. The goal is to gain a better understanding of cancer in the future and to be able to provide improved treatment. The recorded data can be used, for example, to investigate whether cancer is becoming more or less common in Switzerland over time, or whether there are regional clusters of cancer cases. The information obtained from the data will help to develop early detection or prevention measures and ensure that patients receive optimum initial and follow-up care, and it will also support research in this field. "Medical care" refers to the medical services that are provided to safeguard a person's health – for instance, ensuring that the best possible treatment is given. "Follow-up care" means that the patient continues to receive medical care after the cancer has been treated, e.g. in the form of follow-up examinations. Follow-up care is especially important for children and adolescents who have had cancer in the past because depending on the cancer and the way it was treated, complications may develop over time. Long-term complications are health problems that develop years after the cancer occurred, e.g. cardiovascular diseases, infertility, impaired hearing or psychiatric problems.

Is cancer registration for children different from adult registration? Why?

Cancer is rare in children and adolescents. Every year about 400 children and adolescents develop cancer in Switzerland. The mean age at which it occurs is five, with boys affected slightly more often than girls. Children develop different cancers compared to adults. The most common types of cancer in children are leukaemia, brain tumours, lymphomas and a number of rare cancers that develop from immature embryonal tissue that is not found in adults. It is necessary to compile data at a national level not only for cancer registration in children and adolescents but also for cancer monitoring, health reporting and scientific studies. This is why the Cancer Registration Act provides for the registration of cancer in children and adolescents under 20 years of age in the Childhood Cancer Registry. Cancer in adults is recorded in the cantonal cancer registry of the canton in which the patient lives.

Who is behind the Childhood Cancer Registry? What do they do, and why?

The Childhood Cancer Registry (CCR) is a national registry that records cancer in children and adolescents. It records new cases and data about the entire course of the disease and its treatment. The Cancer Registration Act requires doctors and hospitals to report all cases of cancer diagnosed in children and adolescents under 20 years of age to the Childhood Cancer Registry. Registration that is as complete as possible enables reliable conclusions to be drawn about the development of different types of cancer, their course and the efficacy of treatments.

Persons with a reporting obligation, cantonal cancer registries, National Agency for Cancer Registration, Federal Statistical Office – who are they? What do they do, and why?

- **Persons with a reporting obligation** are doctors, hospitals, institutes of pathology and medical laboratories that diagnose and/or treat cancer. These persons send the data to the responsible cancer registry (Childhood Cancer Registry or a cantonal cancer registry).
- The cantonal cancer registries record cancer in adults (from 20 years of age) who live in the canton where the cancer registry is based. They also record new cases and data about the disease and treatment. The cantonal cancer registries report cases of cancer that occur in Switzerland to the National Agency for Cancer Registration on an annual basis.
- The **National Agency for Cancer Registration (NACR)** is the national office that compiles the data on all the cases of cancer that occur in Switzerland. It reviews the quality of the data and provides feedback about it to the cancer registries. The National Agency for Cancer Registration and the Childhood Cancer Registry are responsible for national **health reporting**. Both the National Agency for Cancer Registration and the Childhood Cancer Registry supply the data required for national cancer monitoring to the Federal Statistical Office.
- The **Federal Statistical Office** is the national centre of excellence for public statistics in Switzerland. It receives the cancer data required for **national cancer monitoring** from the National Agency for Cancer Registration and the Childhood Cancer Registry. National cancer monitoring covers data about:
 - **Incidence:** The number of new cancer cases in Switzerland within a certain period.
 - **Prevalence:** The number of cancer cases present in Switzerland at a certain point in time.
 - **Mortality:** The number of deaths in Switzerland within a certain period.
 - **Survival:** Survival rate of patients after a diagnosis of cancer.

The aim of everyone concerned (persons with a reporting obligation, Childhood Cancer Registry, cantonal cancer registries, National Agency for Cancer Registration, Federal Statistical Office) is to ensure that registration is as comprehensive as possible so that reliable conclusions can be drawn about the development of different types of cancer, their course and the efficacy of treatments.

What data are recorded about me or my child?

The following information is recorded about children and adolescents under 20 years of age who have cancer:

- **Personal data**, such as last name, first name, date of birth, gender, social security number (AHVN13) and address.
- **Reporting doctor** or the person who reported the data to the Childhood Cancer Registry: Name and contact details of the doctor who made the diagnosis and/or the doctor treating the patient and the hospital in which he or she works.
- **Cancer diagnosis**, i.e. what type of cancer it is, what characteristics it has, how advanced the disease is (stage), why the diagnosis was made (reason for the diagnosis), how the diagnosis was made, date on which the patient was informed, occurrence of metastases and relapses and their location and whether previous and concomitant diseases were diagnosed.
- **Therapy**, i.e. what treatment was given and with what objective, reasons why the patient is being treated this way (therapy decision), when the treatment started and what it achieved (outcome of therapy, e.g. cure) and what follow-up investigations were carried out after treatment.

How does the Childhood Cancer Registry process my or my child's data?

The federal government has requested the Childhood Cancer Registry to register cancer in children and adolescents under 20 years in Switzerland. The data passed on to the Childhood Cancer Registry by the reporting doctor is registered by the cancer registry after the three-month waiting period (see the paragraph below for an explanation) has elapsed. More information is added to the registered data, e.g. the cancer diagnosis is classified according to international standards (coded) and updated, and the address is checked using the cantonal and communal registers of residents. The Central AHV Compensation Office checks the patient's life status. The Childhood Cancer Registry can also ask the reporting doctor to provide any missing information. The statistics on cause of death kept by the Federal Statistical Office and the medical statistics kept by the hospitals are used to check for any cases of cancer that have not been reported so that they can be registered subsequently. Once a year, for information purposes, the Childhood Cancer Registry reports cases of cancer in children and adolescents under the age of 20 to the cantonal cancer registry in the canton in which the young person is living.

What is the "waiting period"?

The waiting period is a three-month period starting on the day on which you were informed about cancer registration by the doctor treating you (or another medical professional). The waiting period gives patients and their legal representatives time to consider whether they agree to their data or their child's data being registered. The Childhood Cancer Registry may not register reported data within this period of time.

How long are my data stored?

The reporting doctor can pass on to the Childhood Cancer Registry extracts of hospital records (e.g. surgical reports, hospital discharge summaries) containing the data that are being reported. The Childhood Cancer Registry may keep these reports for 80 years after the young patients (under 20 years of age) have died.

Data protection – will my data be treated in confidence?

Yes, your data and your child's data will be treated in confidence. Data processing is carried out in accordance with the Cancer Registration Act and the Data Protection Act. The people working for the

Childhood Cancer Registry are bound to secrecy. They are the only ones allowed to process and register personal information about patients (e.g. last name, first name, address and social security number).

How are the recorded data used?

The recorded data are evaluated with the aim of gaining greater understanding of cancer in the future and being able to treat it even more effectively. The recorded data can be used to investigate whether cancer in Switzerland is changing over time, e.g. whether it is becoming more or less common, or whether it is more common in some regions. The knowledge gained in this way helps to ensure optimum initial and follow-up care and to develop early detection or preventive measures. The aim is also for the recorded data to be used for more in-depth research.

What are my rights as a patient or legal representative?

Patients and their legal representatives (e.g. parents) have a right to receive information and a right to submit an objection.

The right to receive information: am I allowed to know whether data about me have been recorded – and, if so, which data?

As a patient or legal representative you are entitled to be informed by the Childhood Cancer Registry whether data about you and your child have been recorded – and, if so, which data. If you would like to have information about the data concerning you and your child that have been recorded, please complete our information form, sign it and send it as described here to the Childhood Cancer Registry.

The right to submit an objection – what does that mean?

As a patient or legal representative, you are entitled to object to your data or your child's data being registered at any time. If you would like to submit an objection, you need to let us know in writing, i.e. by sending us a letter or an email. You can use the standard form to do this. Your written objection must contain the following information about the patient: first name and last name, address, date of birth, social security number (AHVN13). If you like, you can tell us why you are submitting this objection, but this is not compulsory. The written objection must be signed; a parent or legal representative signs on behalf of children/adolescents under 18. Adult patients (over 18) sign themselves. Objecting to your data being registered will not affect the way you or your child are treated. Once the Childhood Cancer Registry has received your written objection, it will inform you in writing that your objection has been noted.

I have submitted an objection – what happens now with my and my child's data?

The Childhood Cancer Registry distinguishes between three scenarios here:

1. You submit an objection as a healthy person:

As a healthy person you are entitled to submit an objection for yourself or your child even before cancer has been diagnosed. If you or your child develop cancer later in life, the objection you submitted previously will be respected. The Childhood Cancer Registry will not register any data about you or your child. The Childhood Cancer Registry will only report the age in years at which the diagnosis was made, the gender, the place of residence and – where this information has been provided – the reason for the objection to the National Agency for Cancer Registration for statistical purposes.

2. You submit an objection during the waiting period:

The waiting period is a three-month period starting on the day on which you were informed about cancer registration by the doctor treating you (or another medical professional). If you submit an objection to the Childhood Cancer Registry within this

three-month period, no data about you or your child will be registered. The Childhood Cancer Registry will only report the age in years at which the diagnosis was made, the gender, the place of residence and – where this information has been provided – the reason for the objection to the National Agency for Cancer Registration for statistical purposes.

3. *You submit an objection after the waiting period has elapsed:*

If three months have passed since the doctor (or a medical professional) treating you informed you about cancer registration, the waiting period has elapsed. At this point the data reported to the Childhood Cancer Registry by the doctor has already been registered. If you submit an objection after the waiting period, your data will be anonymised. This means that it is no longer possible to identify a person from these data. Here too, the Childhood Cancer Registry will only report the age in years at which the diagnosis was made, the gender, the place of residence and – where this information has been provided – the reason for the objection to the National Agency for Cancer Registration for statistical purposes.

Can I withdraw my objection?

You can withdraw your objection at any time. To do this, simply contact the National Agency for Cancer Registration.

How long is my objection valid?

Your objection remains valid beyond your death or until you retract it.