



Nationale Krebsregistrarungsstelle
Organe national d'enregistrement du cancer
Servizio nazionale di registrazione dei tumori
National Agency for Cancer Registration

Information on the registration of cancer diseases for patients

You as a patient or as a legal representative (e.g. parents) have the right to be informed about the cancer registration and to lodge an appeal if necessary. You also have the right to receive information about the registered data.

1. Is there a legal basis for the cancer registration?

Yes, the Cancer Registration Act (CRA; SR 818.33; in force since January 2020). It governs the registration of meaningful and reliable data on cancerous diseases in Switzerland.

2. Who informs me, the patient?

The medical specialist, who informs you of the diagnosis, is responsible for informing you. It may be e.g. the treating physician. However, this person may also charge a medical specialist with your information.

3. As a patient, what will I be informed of?

You will be informed of your rights guaranteed in the Cancer Registration Act, on the protection of your personal data and on the meaning and purpose of the cancer registration.

4. As a patient, how will I be informed?

You will be informed verbally and will receive a patient information brochure.

5. Why is there a national cancer registration?

The first systematic cancer registrations in Switzerland were made already in 1970 at the regional and cantonal levels. The ever increasing numbers of registers (9 registers in 1980, 13 registers in 2000, 15 registers in 2007), although well-coordinated and certainly of help to the learning process, led to very different practices and working procedures in spite of the concerted coordination. Moreover, registration in the cantons was on a voluntary basis, with the result that not all cantons had a register. Consequently, it was difficult to compare the required data and to obtain a national overview.

The Act therefore now governs the collection, registration and transfer of data at the national level for evaluation and publication. This enables firstly the nationwide, complete and comprehensive cover of all newly diagnosed incidences of cancer as well as the monitoring of the progress of the disease. Secondly, the data to be registered are standardised, thereby facilitating the evaluation for the whole of Switzerland.

This will also enable the data to be processed in the cantons according to uniform legal and organisational conditions, and at the same time ensures uniform protection of the personal rights of patients. This improves the quality of the data concerning cancerous diseases in Switzerland.



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6. Cancer registration for children and adolescents – is it different from that of adults? Why?

Cancerous diseases are rare in children and adolescents. Approximately 400 children and adolescents per year contract cancer in Switzerland. The mean age for disease onset is at five years; boys are more frequently afflicted than girls. Children are afflicted by different types of cancer than adults. Children are most often afflicted by leukaemia, brain tumours, lymphomas and a number of rare tumours from immature embryonic tissue which do not exist in adults. Data need to be collected at the national level for the registration of cancerous diseases in children and adolescents as well as for cancer monitoring, health reporting and for scientific investigations. Accordingly, the Cancer Registration Act stipulates that cancerous diseases diagnosed in children and adolescents are registered in a specific register, the Childhood Cancer Registry. More detailed information can be found on its internet site (www.childhoodcancerregistry.ch).

7. Who are those obligated to report, Cantonal Cancer Registries, Childhood Cancer Registry, Federal Statistical Office? What do they do and why?

- **Those obligated to report** are doctors, hospitals, pathology institutes and medical laboratories that diagnose and/or treat a cancerous disease. Those obligated to report transmit the data to the competent cantonal registry (Cantonal Cancer Registry or Childhood Cancer Registry).
- The [Cantonal Cancer Registry](#) record cancerous diseases and the treatments thereof for adults (aged 20 and above), who live in the canton of the relevant cancer registry. Each year the Cantonal Cancer Registries transmit data on the cancerous diseases registered in Switzerland to the National Agency for Cancer Registration.
- The [Childhood Cancer Registry](#) is the national office for all questions and evaluations relating to cancer in children and adolescents. In addition, it records information on all cancer-afflicted children and adolescents (up to 19 years old) in Switzerland. New cases of cancer and data on the overall course of the disease and its treatment are recorded. Once a year the Childhood Cancer Registry transmits the data to the cantonal cancer registries.
- The [Federal Statistical Office](#) is the national competence centre for public statistics in Switzerland. With the support of the National Agency for Cancer Registration and the Childhood Cancer Registry it publishes each year the national statistics on cancerous diseases (cancer monitoring) including the following data:
 - **Incidence:** The number of new cases of cancerous diseases in Switzerland within a specific *period of time*.
 - **Prevalence:** The number of persons diagnosed with cancer who live in Switzerland at a specific *point in time*.
 - **Mortality:** The number of deaths in Switzerland within a specific *period of time*.
 - **Survival:** Survival of patients after cancer diagnosis.

All the organisations have the common aim to ensure registration in a complete and exhaustive manner as possible, in order to be able to draw reliable conclusions on the development of the various types of cancer, their course and the effectiveness of treatments.



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8. National Agency for Cancer Registration, what is it? What does it do and why?

The National Agency for Cancer Registration (NACR) is a federal organisation that is responsible for defining the standards for cancer registration, and in which the data on all cancerous diseases that appear in Switzerland are collated. The agency checks the quality of the data and reports them back to the cancer registries. The National Agency for Cancer Registration and the Childhood Cancer Registry are responsible for health monitoring at the national level. The health monitoring includes assessments of the cancer-related health status in Switzerland, with the objective to make appropriate recommendations, such as the evaluation of the quality of diagnosis and treatment. The National Agency for Cancer Registration and the Childhood Cancer Registry transmit to the Federal Statistical Office the data on cancer, which are required for the national monitoring of cancer. By order of the Federal Department of Home Affairs (FDHA) the Foundation "National Institute for Cancer Epidemiology and Registration (NICER)" was mandated to carry out the tasks of the National Agency for Cancer Registration (NACR).

9. What information about me will be recorded?

The following information will be recorded for adult cancer patients aged 20 years and above:

- **Personal data** such as your names, first names, insurance number (OASI number), home address and postcode, date and place of birth, gender, marital status, nationality.
- This information is required to register your case correctly. It is anonymised (this means it cannot be linked to you) before it is passed on by the cantonal register to the national agency because it is not needed for evaluation purposes.
- **Data on persons or institutions subject to reporting obligations** such as the name of the institution (if not in their own private practice), names, first names, telephone number, address and e-mail address.
- **Cancer diagnosis**, i.e. the type of cancer, the characteristics of the tumour, how advanced is the disease (stage of disease), why the diagnosis was made (reason for the diagnosis), how the diagnosis was made, the appearance of metastases and recurrences and their localisation, date of your information.
- *Breast, prostate and colorectal cancer cases make up almost half of all cancerous diseases in Switzerland.* For this reason, the following additional data are registered for these three types of cancer: familial or case-contingent predispositions (has this type of cancer already appeared in your family?) and detected pre- and co-morbidities. *For children* these data and still other information (e.g. additional treatments, aftercare) are registered for all types of cancer.
- **Treatment**, i.e. what treatment was given and with what aim, information, why this treatment was made (treatment decision) and when the treatment began. *For children* additionally what the treatment provided (outcome of the treatment e.g. cure) and which follow-up examinations were carried out.

10. Waiting period – what does it mean?

The waiting period allows you time to think about whether you agree to your data being registered. It lasts for three months, beginning from the day when your doctor (or medical specialist) informed you about registering your data in the cancer registry. During this waiting period the competent cantonal cancer registry is forbidden to register your data.



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11. What are my rights as a patient or legal representative?

As a patient or legal representative you have a right to object and a right to information on the data that concern you.

11.1. Right to object – what does that mean?

As a patient or legal representative you have a right to object at any time to the data registration. If you want to lodge an objection you must inform a cancer registry in writing, i.e. by letter or by e-mail (Cantonal Cancer Registry or Childhood Cancer Registry). Your written objection must contain the following information: names and first names, home address, date of birth, insurance number (OASI 13 number). It must be signed and dated. Information on gender and the reason for the objection are voluntary. There is a standard form you can use that is available on the internet sites of [the Cantonal Cancer Registry and the Childhood Cancer Registry](#). Your objection has no influence on your treatment (your doctor will not be informed of your objection). You will then receive a letter from the competent cancer registry confirming that your information will no longer be collected.

11.2. I have lodged an objection – what happens to my data?

The Cancer Registration Act differentiates between three scenarios:

- 1. You lodge an objection as a person without cancer:*

You have the right to lodge an objection as a person without cancer. If later in life you are afflicted with cancer your previously lodged objection remains valid. The Cantonal Cancer Registry then registers none of your data. The Cantonal Cancer Registry, solely for statistical purposes without personal identifying data, registers your age, your gender, your place of domicile and – when given – the reason for your objection at the National Agency for Cancer Registration.
- 2. You withdraw permission within the waiting period:*

The waiting period lasts for three months, beginning from the day when your doctor (or medical specialist) informed you about registering your data in the cancer registry. If you lodge an objection at a cancer registry within these three months, your data will not be registered. The Cantonal Cancer Registry, solely for statistical purposes without personal identifying data, registers your age, your gender, your place of domicile and – when given – the reason for your objection at the National Agency for Cancer Registration.
- 3. You lodge an objection after the end of the waiting period:*

If three months have passed since your doctor (or medical specialist) informed you about registering your data in the cancer registry, then the waiting period has elapsed. At this point in time, the data notified by your doctor to the cantonal cancer registry would have already been registered. If you lodge an objection after the waiting period has elapsed, your already registered data will be rendered anonymous. This means that these data can no longer be attributed to a specific person. Here as well, the Cantonal Cancer Registry, solely for statistical purposes, registers your age, your gender, your place of domicile and – when given – the reason for your objection at the National Agency for Cancer Registration.



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11.3. Can I also withdraw my objection?

You can change your mind at any time and withdraw your objection. If you want to do this, simply contact a cantonal cancer registry or the Childhood Cancer Registry.

11.4. How long will my objection last?

Your objection also remains after your death or as long as you do not withdraw your objection.

11.5. Right to information – what does this mean?

As a patient or as a legal representative you have the right to obtain information from the cantonal cancer registry on whether, and if so, which data have been recorded about you. For this an application can be submitted to the competent [cantonal cancer registry](#) (right to information).

12. Data protection – will my data be treated confidentially?

Yes, your data will be treated confidentially. Cancer registries follow strict rules when receiving, storing and processing information about you. These rules are stipulated in the Cancer Registration Act and in the Data Protection Act. For example, how the information is stored, who is permitted to use the information and when the information will be deleted. Moreover, employees of the cancer registries are subject to professional secrecy. Only they may process and register your personal information (e.g. names, first names, home address). Health insurance providers, insurance companies and employers, for example, do not have access to this information. Data protection is in line with the standards and laws that are in effect in Switzerland.

13. How does the competent cantonal cancer registry process my data?

The competent cantonal cancer registry is assigned by the canton with the task of registering cancerous diseases in adults aged 20 and above in the relevant canton of residence of the patient. The data transmitted by the notifying doctor to the competent cantonal cancer registry are registered by the cancer register after the three-month waiting period has elapsed (see paragraph “Waiting period – what does it mean?”) The registered data are supplemented, e.g. by classification (coding) according to international Standards and/or by matching the address with the help of the cantonal and communal population register. The proof of life is checked by the Central Compensation Office. The competent cantonal cancer registry may also request missing information from the notifying doctor. With the help of the cause-of-death statistics of the Federal Statistics Office and the medical statistics of hospitals and data from early screening programmes an examination will be made on whether cases of cancer were not notified, such that these can be subsequently registered. Each year, the cantonal cancer registries notify the registered cancerous diseases to the National Agency for Cancer Registration.

14. How long will my data be saved?

The notifying doctor can transmit to the competent cantonal cancer registry extracts from medical files (e.g. operation reports, hospital discharge reports) that contain the data to be notified. In cases where the transmitted documents contain information that is not relevant to cancer, the documents in question are either promptly deleted or redacted. The notified reports may be retained in the cantonal



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cancer registries up to 30 years after the death of the adult patients (diagnoses made for patients aged 20 and above). For children and adolescents (diagnoses made before their 20th year), the Childhood Cancer Registry may retain the notified reports for up to 80 years after the diagnosis).

15. How are the nationwide-collected data utilised?

The collection of meaningful, reliable data is the prerequisite for monitoring the nationwide development of cancerous diseases over the coming years. The aim is to gain a better understanding and enable even better treatment of cancerous diseases in the future. The collected data will enable e.g. evaluations of whether cancerous diseases in Switzerland increase or decrease, or whether they occur more frequently in certain regions. Tobacco-related death rates from cancer which were higher in French-speaking Switzerland than in German-speaking Switzerland, or the assessment of the link between asbestos and pleural cancer, are pertinent examples. The knowledge gained contributes to the development of early detection or preventative measures (e.g. this has led to some success for breast cancer or colorectal cancer) and to ensure an optimal medical treatment and after-care, and moreover is intended to support research. Medical treatment is understood to mean medical services that safeguard a person's health, e.g. by being treated in an optimal manner. After-care means that the cancer-afflicted patient continues to be medically supported, e.g. by "after-care examinations". After-care is important, particularly for children and adolescents who previously suffered from cancer, as, depending on the type of cancer and treatment, long-term effects may appear. Long-term effects are health problems such as cardiovascular diseases, sterility, hearing disorders or psychic problems, which may still arise even years after the cancerous disease.