



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



Kinderkrebsregister
Registre du cancer de l'enfant
Registro dei tumori pediatrici
Childhood Cancer Registry

Information about the registration of cancer

Why is information about cancer collected?

It's important to collect information about tumours, i.e. cancer and the preliminary stages of cancer. This information helps to improve the diagnosis, treatment and after-treatment care of these diseases. Since January 2020 there has been a law in Switzerland that regulates the registration of information about cancer. This law requires healthcare professionals to send certain information about your disease to the cancer registry. A cancer registry is a kind of table in which all the important information about cancers is entered.

In Switzerland there are Cantonal Cancer Registries and a Childhood Cancer Registry.

- The Cantonal Cancer Registries collect information about cancer in adults aged 20 or older.
- The Childhood Cancer Registry collects information about cancer in children and adolescents under 20 years of age.

What happens to the collected information?

The collected information assists in the fight against cancer.

The Childhood Cancer Registry and the National Agency for Cancer Registration evaluate the information collected throughout Switzerland. This makes it possible to tell, for example, whether:

- cancer occurs more frequently in a certain part of Switzerland,
- certain types of cancer become more or less common over the years,
- certain other diseases accompany cancer.

The Childhood Cancer Registry and the National Agency for Cancer Registration inform the Swiss population about these developments. Doctors, research scientists and politicians can also learn more about cancer in this way. The aim is to help people with cancer. Collecting and evaluating information about cancer brings us one step closer to this goal. The information helps to answer questions, such as:

- How can cancer be detected early in order to increase the chance of a cure?
- How can cancer treatment be improved?

What information is recorded in the cancer registry?

About the person

- your names / your address / your date of birth / your gender / your insurance number (AHV or OASI number)

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 because it is not needed for evaluation purposes.

About the cancer

- what type of cancer you have,
- when and how the cancer was discovered.

About the treatment

- how your cancer is being treated,
- the date your treatment started.

Additional information about breast, bowel or prostate cancer

- whether cancer has already occurred in your family,
- whether you have other medical conditions at the same time.

Additional information about children and adolescents (under 20 years of age)

- whether the children and adolescents have other medical conditions at the same time,
- whether they are being treated, and if so when and how,
- what the result of treatment was (e.g. a cure),
- what tests were performed after the cancer had been treated (to see, for example, whether the cancer returned, or whether there are any negative effects of the treatment).

How is this information protected?

Cancer registries follow strict rules when receiving, storing and processing information about you. These strict rules are described in the Cancer Registration Act. For example, this law states how the information is stored, who is permitted to use the information and when the information is deleted. Health insurance providers and employers do not have access to this information. Data protection is in line with the standards and laws that are in effect in Switzerland.

Can I see the information about me in the cancer registry?

You can see everything that is known about you in the cancer registry. If you would like to see the information about you, please write to a cancer registry for details of the procedure.

If you are an adult, the cancer registry in the canton where you live will be happy to assist you. You can find the address of your canton's cancer registry online (address list): www.nacr.ch/en/cancer-registration/cancer-registries. You can also get information from the National Agency for Cancer Registration by e-mail nacr@nicer.org or by phone 044 634 53 74.

For information about children and adolescents you can contact the Childhood Cancer Registry by e-mail kinderkrebsregister@ispm.unibe.ch or by phone 031 631 56 70.

Waiting period

The three-month waiting period begins once you have received this brochure. This waiting period allows you plenty of time to think about whether you agree to your data being registered.

Do you agree to your data being registered?

If so, no further action is needed.

Do you object to your data being registered?

If you don't want your data to be registered, you must inform a cancer registry in writing. To do so, there is a form you can use that is available from your Cantonal Cancer Registry or from the Childhood Cancer Registry. You need to complete and sign it and send it to a cancer registry. You will then receive a letter from the cancer registry confirming that your information will no longer be collected.

If you withdraw permission within the waiting period, your data will not be registered. If you only withdraw permission at a later date, i.e. after the waiting period has elapsed and when the cancer registry has already registered your data, the cancer registry will immediately delete all data concerning your *person*. Data concerning your *disease* will remain in the register. However, the person to whom this data belongs will no longer be identifiable. Moreover, after this point in time, no further data concerning yourself or your disease will be registered.

Objecting to your data being collected and used will not affect the way your cancer is treated. You can change your mind at any time and withdraw your objection. If you want to do this, please contact a cancer registry.

How can I find out more about cancer registration, and who can answer my questions?

You can find more information about cancer registration on the websites

- of the Cantonal Cancer Registries (address list): www.nacr.ch/en/cancer-registration/cancer-registries
- of the Childhood Cancer Registry: www.kinderkrebsregister.ch
- of the National Agency for Cancer Registration: www.nacr.ch/en/cancer-registration

For questions about cancer in children and adolescents

- Childhood Cancer Registry (ChCR)
Mittelstrasse 43, CH-3012 Berne
e-mail kinderkrebsregister@ispm.unibe.ch
phone 031 631 56 70

For questions about cancer in adults

- National Agency for Cancer Registration (NACR)
Hirschengraben 82, CH-8001 Zurich
e-mail nacr@nicer.org
phone 044 634 53 74

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This information for patients can be downloaded in 13 other languages from:
www.nacr.ch/en/cancer-registration/patients