

Information on the registration of cancers

Information sheet for providing
patients and their representatives
with official information.

You can find further details in the comprehensive
information for patients on our website at www.nacr.ch,
in German, French, Italian and English.



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

Your contribution to better healthcare

The brochure informs you about the legal requirement to register benign tumours, precancerous stages and cancer. This covers a broad spectrum of cases. If you are given this brochure, it doesn't automatically mean that you have a malignant cancer!

The registration of cancers is based on the Federal Act on the Registration of Cancerous Diseases (Cancer Registration Act, CRA). Under this law, doctors, hospitals and laboratories must send information about cancers to the responsible cancer registry. In this factsheet we explain how the cancer registration works and about your right to be informed, view your own data and object to the registration.

Information about cancer is collected and evaluated by the Cantonal Cancer Registries and the Childhood Cancer Registry. The data are then summarised by the National Agency for Cancer Registration and the Childhood Cancer Registry and processed.

Why are your data registered?

By providing your data you are making an important contribution to ensuring that all cancers are recorded as fully as possible. You are helping to improve care for everyone, to understand cancer and to beat it.

1. Your right to information: what is recorded?

The Cantonal Cancer Registries and the Childhood Cancer Registry compile information about the person and the cancer. The following types of information are recorded:

- Information about the person (e.g. name, address, date of birth, OASI number)
- Information about the cancer (e.g. type and spread of the tumour, treatment to date, course of the disease)

Additional information is recorded for breast, colorectal or prostate tumours and for children and adolescents under 20 years of age.

These data are regularly supplemented and updated based on comparisons with external lists (hospital lists, population lists, etc.).

NOTE:

Most of your personal details (name, address, exact date of birth, OASI number) are removed before the data are forwarded to the National Agency for Cancer Registration.

2. Your right to view your data: this is how you access your own data

You can view your own data in the cancer registry at any time.

If you want to view your data, contact the cancer registry in your canton. Contact the Childhood Cancer Registry if you want to see data about children and adolescents (www.childhoodcancerregistry.ch).

3. Your right to object

You can submit an objection in writing at any time if you do not want your data to be registered. An objection remains valid throughout your lifetime and throughout Switzerland. You can also withdraw your objection at any time.

If you submit an objection within three months of your data being received by a cancer registry, they are not recorded but are destroyed. If you submit an objection later than three months after your data have been received by a cancer registry, your personal details are deleted immediately. The information about your cancer remains in the registry.

The fact that an objection has been submitted is noted, and no further data are registered from the time of the objection.

This is how you submit an objection:

1. Request the objection form from a Cantonal Cancer Registry, the Childhood Cancer Registry or the National Agency for Cancer Registration or download the form here: www.nacr.ch/downloads.
2. Complete and sign the form.
3. Send the form to a Cantonal Cancer Registry or to the Childhood Cancer Registry.

You do not have to give any reasons for your objection. The Cancer Registry will then send you written confirmation.

The addresses of the Cantonal Cancer Registry and the Childhood Cancer Registry can be found on our website at: www.nacr.ch/cancer-registries and on the Objection form.

NOTE:

You can also submit an objection by writing a letter stating your surname and first name, address, date of birth and insurance number and adding the date of writing and your signature.

How the data are protected

Data protection and data use are regulated by laws. The cancer registries are guided by the provisions of the Cancer Registration Act and other laws and rules applicable in Switzerland. The subsequent statistical processing and use for research purposes are subject to clear rules.

How your data are protected:

- The data are stored in separate and secured electronic systems in Switzerland.
- Everyone who works with the data is required to observe confidentiality.
- All data owners have special data protection and security concepts.
- Other people and institutions – such as employers or health insurance providers – do not have access to the information.
- Information for the public is always prepared in such a way that it cannot be used to identify individuals.
- Researchers receive the data only if authorised. If authorisation has not been granted, they only receive the data in anonymised form.

Moreover, information that is not needed by the cancer registry must be destroyed immediately. This means that only data which serve a specific purpose are registered.

Would you like more information?

The National Agency for Cancer Registration is the place to contact if you have any questions about cancer registration or if you need help to exercise your rights. The Childhood Cancer Registry is the place to contact if you have any questions about the registration of cancers in children and adolescents. You can find the addresses of the Cantonal Cancer Registries and the Childhood Cancer Registry on our website at www.nacr.ch/cancer-registries

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Childhood Cancer Registry

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