

# Using your health data to improve treatment for everyone

Information for patients and their representatives about cancer registration

**Official information for patients from the National Agency for Cancer Registration and the Childhood Cancer Registry**



# Your contribution to better healthcare

When you were given this brochure you were told that you have cancer or a precancerous stage. This may have a major impact on your life. Thank you for taking the time to read this short brochure. It will tell you how cancer registration works. It will also tell you about your rights: to be informed, to see your own data, to object to registration.

Cancer is a very common condition and has been the subject of research for many years. The medical care provided is improving all the time. That's why it's important to know as much as possible about how cancer spreads and develops. In Switzerland there are cancer registries, the purpose of which is to generate information about cancer. A cancer registry records all cases of cancer, precancerous stages and benign tumours. Doctors are required to pass on information about your cancer to the responsible cancer registry.

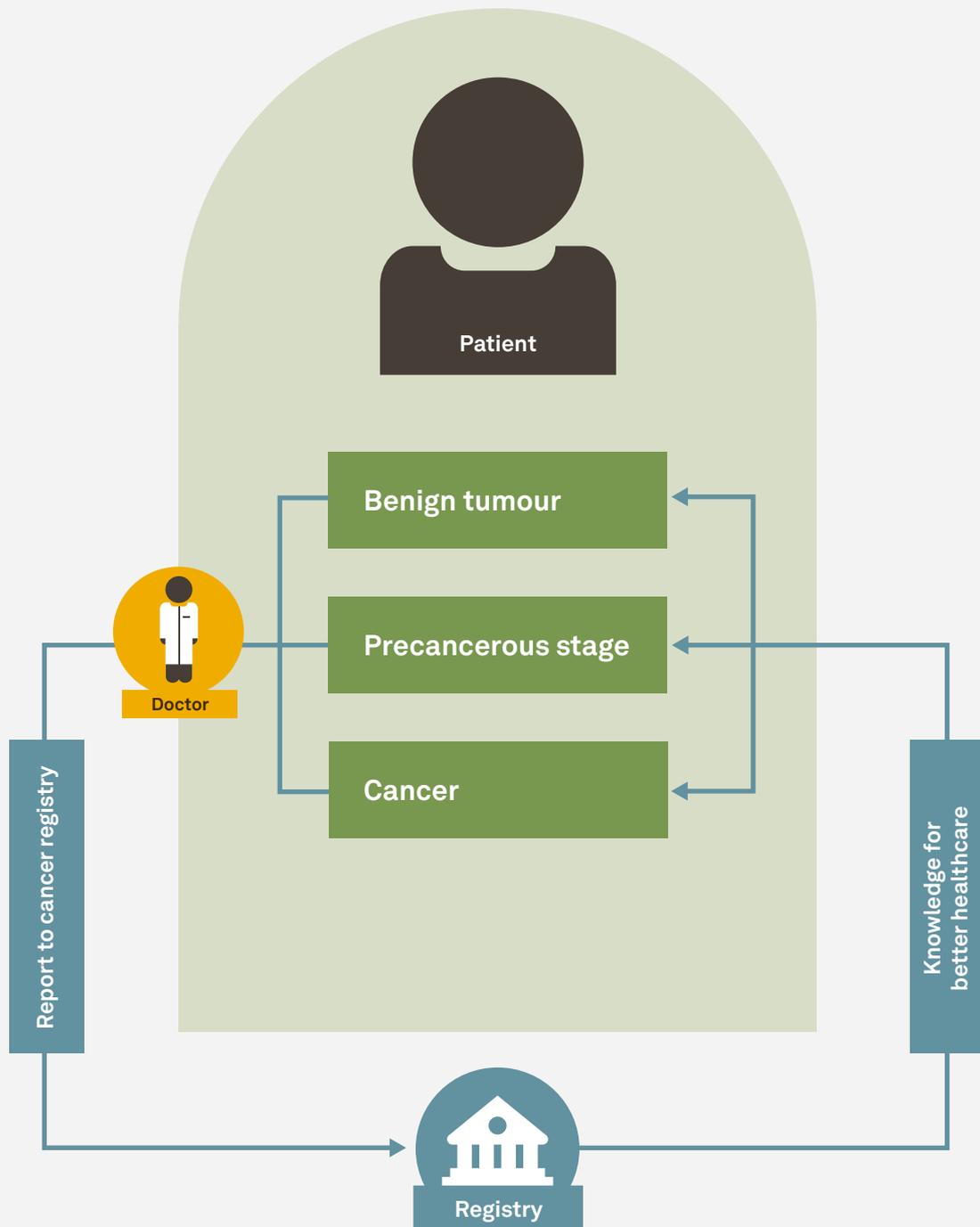
By providing your data you are making an important contribution to ensuring that all cancers are recorded as fully as possible. You are helping to improve care for everyone, to understand cancer and to beat it.

## — PLEASE NOTE:

The National Agency for Cancer Registration, the Childhood Cancer Registry, the Cantonal Cancer Registries and the Federal Statistical Office study how common cancer is in Switzerland and how it develops. They operate on behalf of the Federal Government and in line with the Cancer Registration Act.

### **N.B.:**

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!



You are benefiting from the data provided by several hundreds of thousands of patients. Your data will also help other people who fall ill.



**Cancer registration is an established system. It has been helping to improve healthcare in Switzerland for years.**

# Why do we register data?

**More knowledge means better perspectives for treatment:  
Data about cancer help to improve understanding of cancer  
and to beat it.**

It's important to collect information about cancer, the precancerous stages and benign tumours. This information enables these diseases to be controlled more effectively. The knowledge gained helps to:

- Prevent cancer more effectively,
- Identify cancer at an earlier stage,
- Provide targeted treatment for cancer,
- Align medical care with the cancer,
- Prevent recurrences.

The more completely cases of cancer are recorded, the more informative and useful the data are. This enables us to provide more effective help for people with cancer.

The more data are available, the more accurate the conclusions about cancer become.

## **Legal basis**

Cancer registration has existed at national and cantonal level for a long time. Since January 2020 there has been a law in Switzerland that regulates the registration of information about cancer – the Cancer Registration Act. Under this law, doctors, hospitals and laboratories must send information about cancers to the responsible cancer registry. References for the texts of the legislation mentioned here can be found at the end of this brochure (page 22).

## **Cancer registries are a tried and tested tool**

Cancer registries have repeatedly proven their value in the past. For example, when a large number of cancers developed in a certain region or over a short period of time and nobody knew why. In such cases cancer registries help to identify the cause of such disease clusters and the related health factors. Without cancer registries, unusual developments would perhaps go unnoticed. Past examples of situations in which data from cancer registries were useful include the changes to people's thyroid glands observed after the Chernobyl catastrophe and the link between asbestos and pleural cancer.

Cancer registration also allows the quality of the screening programmes operated in many Swiss cantons to detect breast and colorectal cancer to be evaluated and many other questions about cancer to be answered (see examples on page 9).

# What do the data help to discover?

The data enable us to find out which cancers occur how commonly, how they develop and how good the healthcare provided is. These findings are available to anyone who is interested.

Thanks to the registry data, the general public, doctors and politicians learn more about the incidence and the development of cancer. For example: which cancers occur, how dangerous they are, how they develop over time and how they are treated. This helps to improve the provision of healthcare and to identify and implement the right preventive measures.

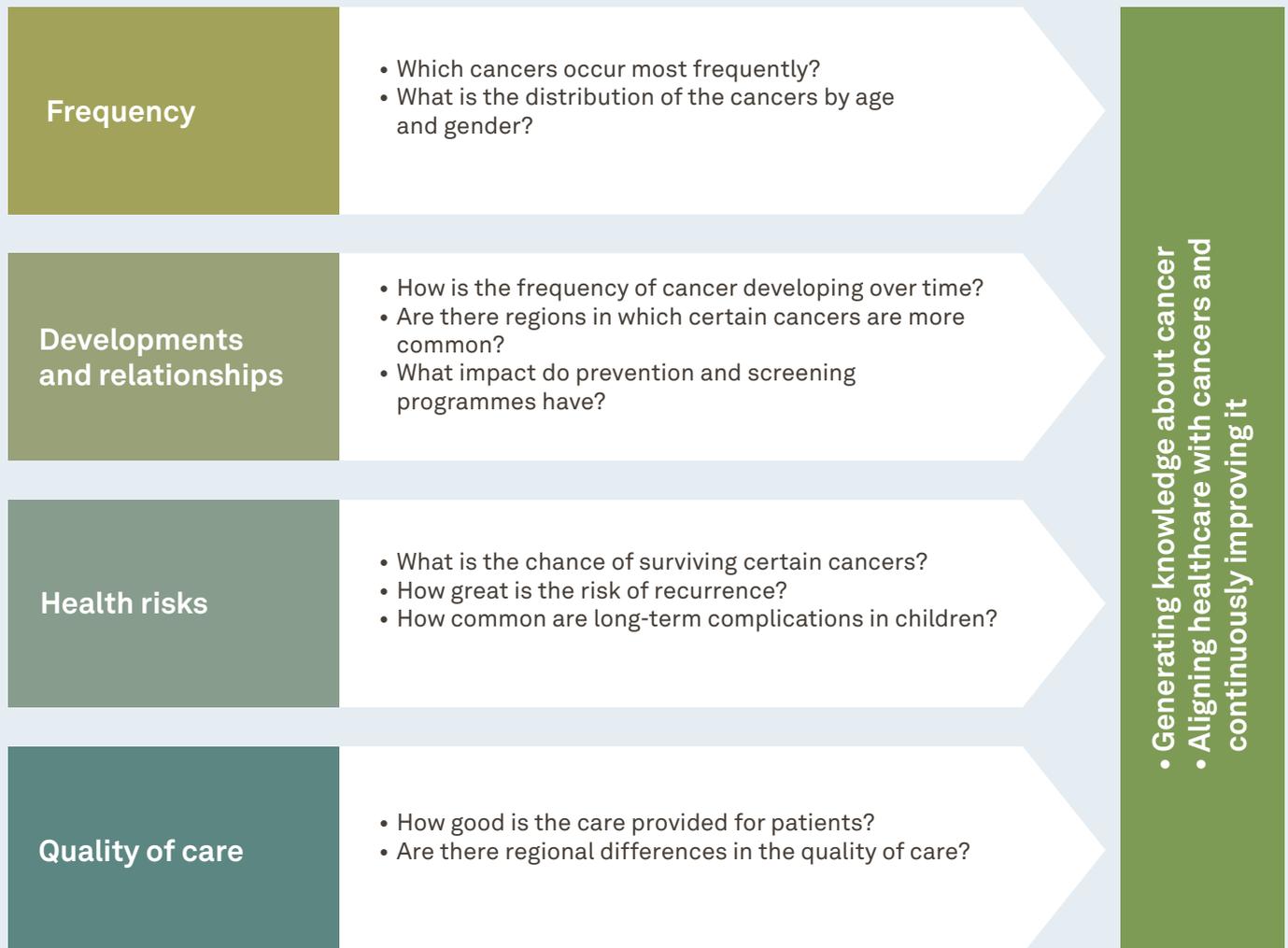
## — PLEASE NOTE:

Sometimes the cancer registries also pass on data to researchers. The researchers perform their own analyses of the data in the course of investigating important questions relating to the way cancer develops. This is governed by strict conditions. The transfer of data is subject to the Swiss Human Research Act and is regulated very precisely.

Sometimes the cancer registries and other organisations carry out research to obtain even more information about the way cancer develops. In such cases they contact people registered in the cancer registry in writing to ask if they would like to participate in these research projects. They can take part voluntarily in research projects.

The knowledge generated from the accumulated data helps to improve the healthcare provided.

Data from the cancer registry can be used to answer the following questions, for example.



# How registration works

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.

In Switzerland there are Cantonal Cancer Registries and a Childhood Cancer Registry. They collect information about the development and distribution of cancer. They only compile the data stipulated in the Cancer Registration Act or a cantonal law.

## **The Cantonal Cancer Registries**

The Cantonal Cancer Registries compile information on cancer in adults from the age of 20 and evaluate it. They transfer the data to the National Agency for Cancer Registration once a year.

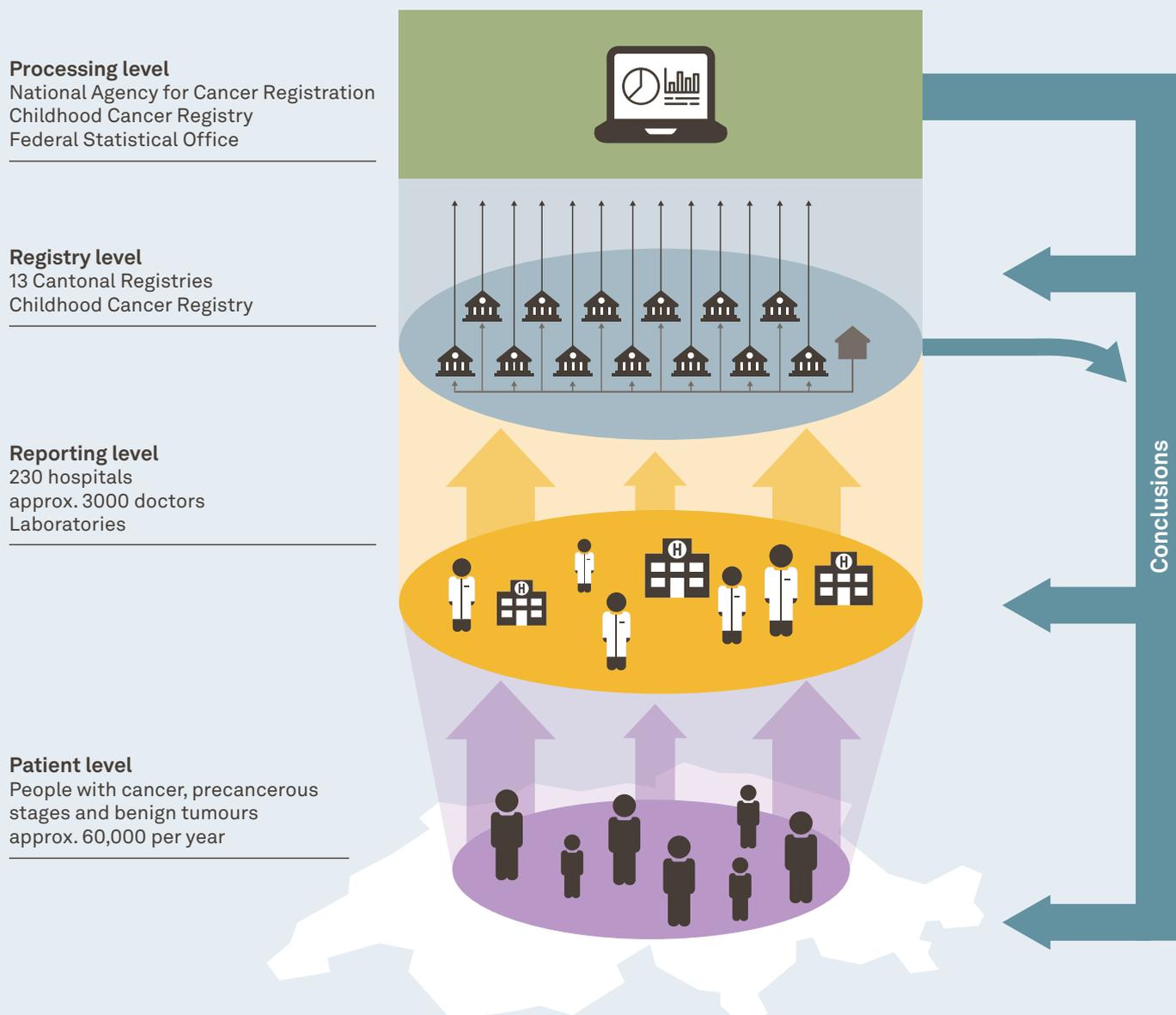
## **The Childhood Cancer Registry**

The Childhood Cancer Registry compiles information on cancer in children and adults under the age of 20 throughout Switzerland and evaluates it. The Childhood Cancer Registry sends its data to the responsible Cantonal Cancer Registries once a year. These transfer the data to the National Agency for Cancer Registration once a year.

## **The National Agency for Cancer Registration**

The National Agency for Cancer Registration checks whether the data from the cancer registries are correct and complete. It then prepares the data for further processing and evaluates them on a national basis.

## How cancer registration and knowledge-sharing work



Data are compiled in each canton by the cancer registries and evaluated on a cantonal and national basis.



## The Cancer Registration Act reinforces patients' rights:

1. to be informed about exactly what is being registered,
2. to see their own data at any time,
3. to not have their data entered in a cancer registry if they do not wish to.

# 1.

## YOUR RIGHT TO INFORMATION

# This is what is recorded

The cancer registries compile information about the person and the cancer. Various additional items of information are recorded depending on the situation and the patient's age.

The cancer registries record the data in keeping with the requirements of the Cancer Registration Act. A distinction can be made between information about the person and information about the cancer. Additional information is recorded depending on the type of cancer and the patient's age. The data are updated continuously.

### Information about the person

The following information is recorded:

Surname	First name
Address	Municipality no.
Date of birth	Place of birth
Gender	Marital status
Nationality	
Insurance number (AHV no.)	

— **PLEASE NOTE:**

The information about you such as your name, address and AHV number is important in ensuring that data are recorded correctly and avoiding duplication of information. For example, if you receive treatment in another canton or switch to another doctor. The link between you and your data (name, address, AHV number) is removed before the data are sent to the National Agency for Cancer Registration.

### Information about the cancer

The following information is recorded:

What type of cancer is it?
How far has the cancer spread?
When and how was the cancer diagnosed?
When and how was the cancer treated?
How is the cancer progressing?

## **Additional information about breast, colorectal and prostate cancer**

In these cases the following additional information is recorded:

Does the patient have any other conditions that could affect treatment?

Does the patient have any known predispositions that are associated with an increased risk of cancer?

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

In these cases the following additional information is recorded:

Does the patient have any other conditions or predispositions that are important for the development of the cancer, the prognosis or treatment?

How well have the treatments worked?

Have there been any long-term complications of treatment?

### **PLEASE NOTE:**

When someone dies, the date and cause of death are additionally recorded. This is done in all cases – irrespective of whether there was a link between the patient’s death and their cancer. The data are updated or checked regularly, for example against the register of residents (personal data, vital status) and with screening programmes (participation, diagnosis), the Central AHV Compensation Office (AHV number, vital status) and the Federal Statistical Office (cause of death) and hospitals (lists of diagnoses).

## **2.**

YOUR RIGHT TO SEE YOUR DATA

## **This is how you access your own data**

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

If you want to see your data, simply get in touch with the cancer registry in your canton. Contact the Childhood Cancer Registry if you want to see data about children and adolescents. Contact details can be found at the end of this brochure (page 21).

# 3.

## YOUR RIGHT TO OBJECT

# This is how you submit an objection

You can submit an objection at any time if you don't want your data to be recorded in the cancer registry. An objection remains valid throughout your lifetime and throughout Switzerland.

You can object at any time to your data being recorded in a cancer registry. If you submit an objection, it remains valid throughout your lifetime and throughout Switzerland. However, you can also withdraw your objection at any time. It is important to note the following principle: If you submit an objection, this does not have any effect on the way your cancer is treated.

A three-month waiting period starts when the cancer registry receives the data reported by your doctor. The cancer registries are not allowed to register reported data within this period of time. This waiting period allows you plenty of time to think about whether you agree to your data being registered.

### PLEASE NOTE:

You can also submit a preventive objection.

## What happens if you submit an objection?

If you submit an objection within three months of your data being reported, they are not recorded but destroyed.

If you submit an objection later than three months after your data have been reported, your personal details are deleted immediately. However, the information about your cancer remains in the registry.

In all cases the fact that a person has submitted an objection is recorded, together with the reason (if the person has given a reason). No further data are recorded from the time the objection is submitted.

### PLEASE 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 to submit an objection

If you do not want data to be registered, you must notify any of the Swiss cancer registries of this in writing (see page 20 for the contact details of the registries). You do not have to give a reason.

How to submit an objection:

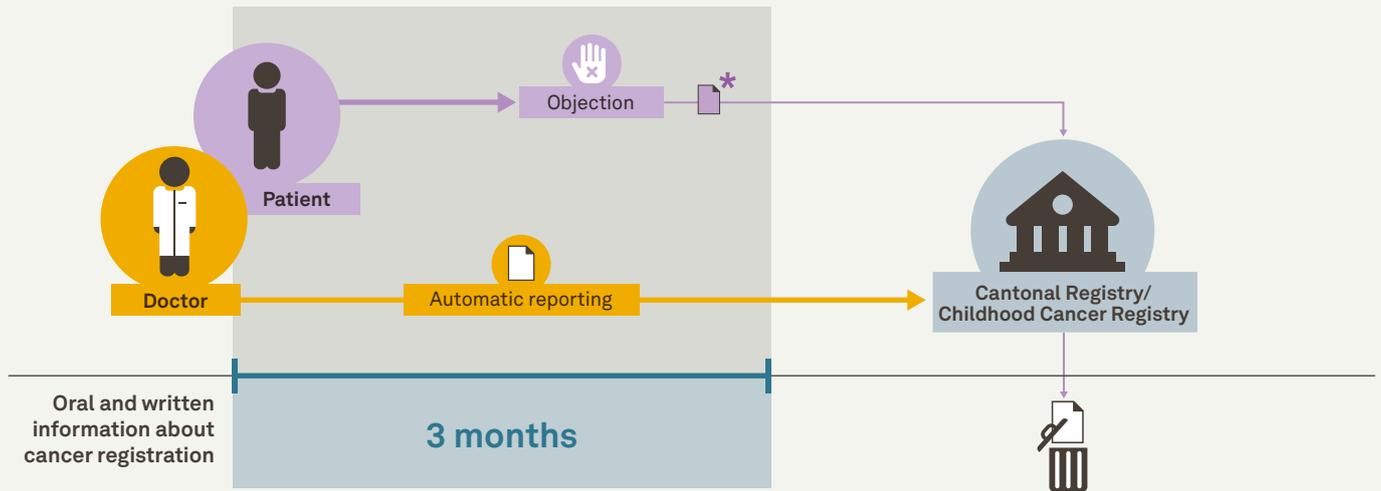
1. Request the objection form from a Cantonal Cancer Registry, the Childhood Cancer Registry or the National Agency for Cancer Registration or download it from [widerspruch.nrks.ch](http://widerspruch.nrks.ch).
2. Complete the form and sign it.
3. Send the form to a cancer registry.

The cancer registry will then send you written confirmation.

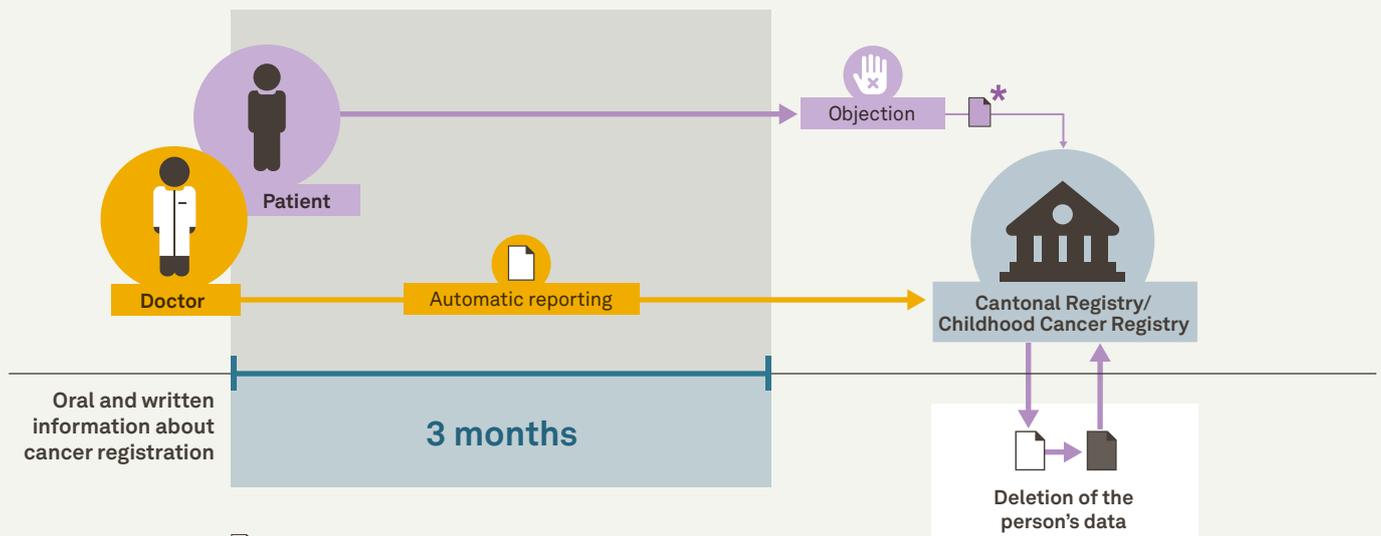
An objection will not affect the medical treatment you receive.

## The right to object

### A Objection within three months after reporting (without registration)



### B Objection more than three months after reporting (the diagnosis is registered without data that could identify the person)



-  Data with details that identify the person
-  Data without details that identify the person
-  Information about objection

\* If someone submits an objection, information about the objection (age, gender, place of residence, reason) is recorded in all cases. This helps to provide an overview of objections.

# How the data are protected

**The cancer registries follow strict rules to protect your data. They are guided by the provisions of the Cancer Registration Act and other laws and rules applicable in Switzerland.**

The Cancer Registration Act forms the legal basis for registering data. It ensures that registration does not entail disadvantages for anyone. The Act regulates how information is entered securely in the cancer registry, how it must be stored, who may see the information, who may use the data and when the information must be deleted. All national and international data protection guidelines naturally apply to cancer registration too.

## **Clear rules protect your data**

This is how personal 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 and 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.

Furthermore, 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.

## **Clear requirements governing statistical processing**

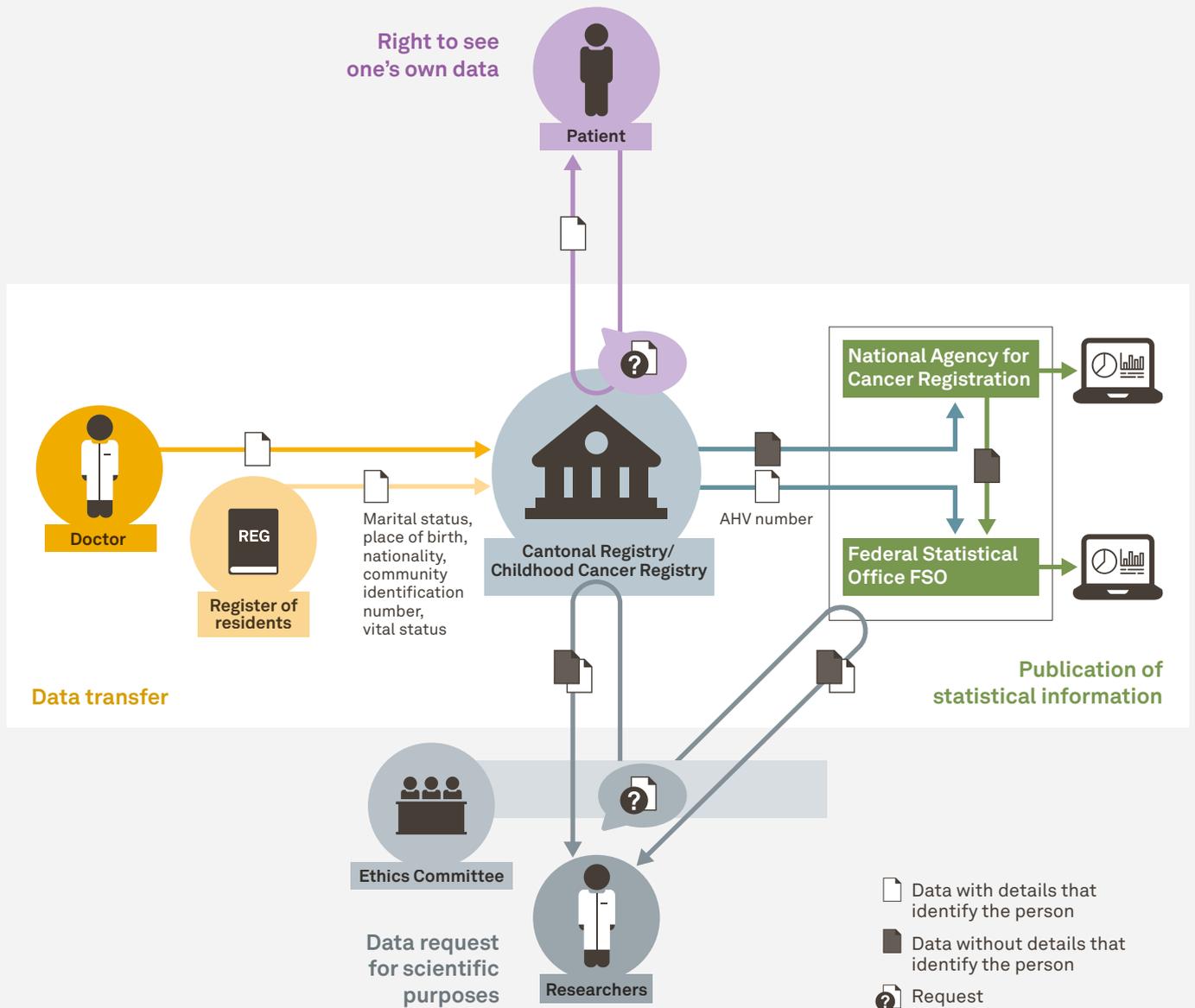
The National Agency for Cancer Registration evaluates the data from the cancer registries using scientific rules. It receives no personal data that could identify an individual. The Federal Statistical Office (FSO) also produces statistics describing the incidence of cancer. It is the only national office permitted to use the AHV number to link data from the cancer registries with data from other sources in order to generate new scientific knowledge.

Data protection and data use are regulated by laws.

### Strict rules governing the use of data for research purposes

On request, the Cantonal Cancer Registries, the Childhood Cancer Registry, the National Agency for Cancer Registration and the Federal Statistical Office also provide data for research projects carried out by third parties, e.g. universities. Data containing personal information may also be provided for such research projects if there are special reasons. However, the provision of data in these cases requires your consent or approval from an Ethics Committee.

### Selected data flows in cancer registration



# 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.

## **National Agency for Cancer Registration**

Website: [www.nacr.ch](http://www.nacr.ch)

E-mail: [info@nkrs.ch](mailto:info@nkrs.ch)

Phone: 044 634 53 74

## **If you need individual support or advice about your medical condition, contact a patient organisation:**

### **Swiss Cancer League**

Website: [www.krebsliga.ch](http://www.krebsliga.ch)

E-Mail: [helpline@krebsliga.ch](mailto:helpline@krebsliga.ch)

Phone: 0800 11 88 11

### **Swiss Patient Organisation Foundation SPO**

Website: [www.spo.ch](http://www.spo.ch)

E-Mail: [info@spo.ch](mailto:info@spo.ch)

Phone: 044 252 54 22

### **Association of Swiss Patient Advice Centres**

Website: [www.patientenstelle.ch](http://www.patientenstelle.ch)

E-Mail: [info@patientenstelle.ch](mailto:info@patientenstelle.ch)

Phone: 044 361 92 56

The Childhood Cancer Registry is the place to contact if you have any questions about the registration of cancer in children and adolescents (see below for contact details).

The addresses of the Childhood Cancer Registry and the 13 Cantonal Cancer Registries are shown here:

**Childhood Cancer Registry (CCR)**

Website: [www.childhoodcancerregistry.ch](http://www.childhoodcancerregistry.ch)

E-Mail: [childhoodcancerregistry@ispm.unibe.ch](mailto:childhoodcancerregistry@ispm.unibe.ch)

Phone: 031 684 56 70

**Aargau Cancer Registry Foundation (krAG)**

Website: [www.krebsregister-aargau.ch](http://www.krebsregister-aargau.ch)

E-Mail: [krebsregister-aargau@hin.ch](mailto:krebsregister-aargau@hin.ch)

Phone: 062 825 27 00

**Basel Cancer Registry (KRBB)**

Website: [www.krbb.ch](http://www.krbb.ch)

E-Mail: [krbb@hin.ch](mailto:krbb@hin.ch)

Phone: 061 267 49 15

**Bern Solothurn Cancer Registry (KRBESO)**

Website: [www.krebsregister.unibe.ch](http://www.krebsregister.unibe.ch)

E-Mail: [bern.krebsregister@unibe.ch](mailto:bern.krebsregister@unibe.ch),

[solothurn.krebsregister@unibe.ch](mailto:solothurn.krebsregister@unibe.ch)

Phone: 031 632 99 75

**Graubünden and Glarus Cancer Registry**

Website: [www.ksgr.ch](http://www.ksgr.ch)

E-Mail: [krebsregister@ksgr.ch](mailto:krebsregister@ksgr.ch)

Phone: 071 242 70 12

**Eastern Switzerland Cancer Registry (KROCH)**

**(St. Gallen, Appenzell Innerrhoden, Appenzell  
Ausserrhoden, Thurgau, Principality of Liechtenstein)**

Website: <https://ostschweiz.krebsliga.ch>

E-Mail: [sekretariat.krebsregister@krebregister-ost.ch](mailto:sekretariat.krebsregister@krebregister-ost.ch)

Phone: 071 242 70 10

**Central Switzerland Cancer Registry**

**(Lucerne, Uri, Obwalden, Nidwalden)**

Website: [www.zentralschweizer-krebsregister.ch](http://www.zentralschweizer-krebsregister.ch)

E-Mail: [krebsregister@luks.ch](mailto:krebsregister@luks.ch)

Phone: 041 205 24 43

**Cancer Registry of the Cantons of Zurich, Zug,  
Schaffhausen and Schwyz**

Website: [www.krebsregister.usz.ch](http://www.krebsregister.usz.ch)

E-Mail: [meldung.krebsregister@usz.ch](mailto:meldung.krebsregister@usz.ch)

Phone: 044 255 56 35

**Fribourg Cancer Registry (RFT)**

Website: <https://fribourg.liguecancer.ch/registre-des-tumeurs>

E-Mail: [registre@liguecancer-fr.ch](mailto:registre@liguecancer-fr.ch)

Phone: 026 425 54 05

**Geneva Cancer Registry (RGT)**

Website: [www.unige.ch/medecine/rgt](http://www.unige.ch/medecine/rgt)

E-Mail: [rgt@hin.ch](mailto:rgt@hin.ch)

Phone: 022 379 49 50

**Neuchâtel and Jura Cancer Registry (RNJT)**

Website: [www.ne.ch/RNJT](http://www.ne.ch/RNJT)

E-Mail: [rnjt@hin.ch](mailto:rnjt@hin.ch)

Phone: 032 717 71 90

**Valais Cancer Registry (RVST)**

Website: [www.ovs.ch](http://www.ovs.ch)

E-Mail: [rvst@hin.ch](mailto:rvst@hin.ch)

Phone: 027 603 49 73

**Vaud Cancer Registry (RVT)**

Website: <https://rvt.unisante.ch>

E-Mail: [rvt@unisante.ch](mailto:rvt@unisante.ch)

Phone: 021 314 73 10

**Ticino Cantonal Cancer Registry (RTTI)**

Website: [www.ti.ch/tumori](http://www.ti.ch/tumori)

E-Mail: [ti.registrotumori@hin.ch](mailto:ti.registrotumori@hin.ch)

Phone: 091 816 25 01

# Legal basis

## Information about the cancer registration legislation (in German, French, Italian)

[www.bag.admin.ch](http://www.bag.admin.ch) > Gesetze & Bewilligungen > Gesetzgebung > Gesetzgebung Mensch & Gesundheit > Gesetzgebung Krebsregistrierung

### Legal texts

- Dispatch to the Federal Act on the Registration of Cancerous Diseases of 29 October 2014
- SR 818.33 Federal Act on the Registration of Cancerous Diseases (Cancer Registration Act, CRA) of 18 March 2016
- SR 818.331 Ordinance on the Registration of Cancerous Diseases (Cancer Registration Ordinance, CRO) of 11 April 2018
- Explanations for the Cancer Registration Ordinance (CRO) of 11 April 2018
- Draft Revision of the Ordinance on the Registration of Cancerous Diseases (Cancer Registration Ordinance, CRO) of 17 November 2021
- Explanations for the Revision of the Cancer Registration Ordinance of 17 November 2021

**PLEASE NOTE:**

All the legal texts can be downloaded in German, French and Italian from the website of the Federal Office of Public Health FOPH (see link above or QR code).



## **Publication details**

### **Published by**

National Agency for Cancer Registration (NACR)  
c/o National Institute for Cancer Epidemiology and Registration  
Foundation (NICER)  
Hirschengraben 82  
8001 Zurich  
Switzerland

Childhood Cancer Registry  
Mittelstrasse 43  
3012 Bern  
Switzerland

### **Publication date**

July 2022 (Version 2)

### **Concept and design**

moxi ltd., Biel

This brochure is available in the following languages:

**German, French, Italian, English**

An abridged version of the brochure is available in the following languages:

**German, French, Italian, Romansh, English, Albanian, Arabic, Polish, Portuguese, Russian, Serbian, Croatian, Spanish, Tamil, Turkish, Plain German, Plain French and Plain Italian**

Orders and downloads:

The publications are available on the migesplus.ch order platform, which you can access via the following link → [www.nacr.ch/order](http://www.nacr.ch/order)

Sincere thanks to the employees at the following institutions for actively supporting the development of this brochure:

- **National Agency for Cancer Registration**
- **Childhood Cancer Registry**
- **The Cantonal Cancer Registries**
  
- **Federal Office of Public Health FOPH**
- **Federal Statistical Office FSO**
- **Conference of Cantonal Ministers of Public Health GDK**
  
- **Swiss Medical Association FMH**
- **Association of Swiss General Practitioners and Paediatricians mfe**
- **Association of Swiss Hospitals H+**
- **Swiss Association against Cancer Oncosuisse**
- **Swiss Society for Quality Management in Health Care sQmh**
  
- **Swiss Cancer League**
- **Swiss Patient Organisation Foundation SPO**
- **Association of Swiss Patient Advice Centres**