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

Description of the legally binding data dictionary for all cancer registries under the new law on cancer registration

Contents

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Abbreviations

ChCR	Childhood Cancer Registry
CR	Cantonal cancer registry
CRA	Cancer Registration Act (SR 818.33)
CRO	Cancer Registration Ordinance (SR 818.331)
FMH	Swiss Medical Association (Foederatio Medicorum Helveticorum)
FOPH	Federal Office of Public Health
NICER	National Institute for Cancer Epidemiology and Registration
NACR	National Agency for Cancer Registration
SGMO	Swiss Society of Medical Oncology
SGPatho	Swiss Society of Pathology
SGR-SSR	Swiss Society of Radiology
SPOG	Swiss Paediatric Oncology Group

Introduction

In the future, cancer cases are to be registered in their entirety and uniformly throughout Switzerland. In March 2016, the Swiss parliament passed the Federal Act on the Registration of Cancerous Diseases (Cancer Registration Act, CRA)[1]. In April 2018, the Federal Council passed the associated ordinance (CRO)[1]. **The obligation to register under CRA/CRO and the system change for data registration in the cantonal cancer registries (CR) and the Swiss Childhood Cancer Registry (CHCR) will come into effect on 1 January 2020**.

All doctors, hospitals and private/public healthcare institutions that diagnose or treat cancer will be required to report selected information on specific types of cancer[2] to the CR and ChCR from 1 January 2020. At the same time, every canton is required to set up a cancer registry or to join an existing one. The cancer registries are obliged to supplement incomplete information by making enquiries with the reporting individuals or institutions. If individual details are deemed unnecessary for the diagnosis and treatment of a patient and have therefore not been recorded, they do not have to be collected and reported purely for the purpose of cancer registration.

The CRA establishes the framework for the collection, registration and evaluation of data on cancer and thus lays the foundations for:

- observation of the temporal development of cancer at population level (trend) and at individual level (course);
- development of effective prevention and screening measures and checking of their effectiveness;
- evaluation of the quality of diagnosis, care and treatment;
- facilitating the planning of public health resources;
- supporting research.

The National Agency for Cancer Registration (NACR) is a federal organisation that is responsible for defining the mandatory data structure and coding guidelines for the CRs and the ChCR. On the basis of Art. 33 CRA and Art. 36 and Art. 37 CRO, these and other tasks of the NACR were transferred to the National Institute for Cancer Epidemiology and Registration (NICER). The CRs, the ChCR, the cantons and medical societies were involved in defining the data structure. The working group for developing the mandatory data structure, which was led by the

[1] The CRA (SR 818.33) and explanations on the CRO (SR 818.331) (in DE, FR an IT only) can be viewed at: https://www.bag.admin.ch/bag/de/home/gesetze-und-bewilligungen/gesetzgebung/gesetzgebung-mensch-gesundheit/gesetzgebung-krebsregistrierung.html [last accessed on 15.10.2019]

[2] CRO Annex 1 (Art. 5 para. 1): Cancer cases to be reported.

federal government from January to December 2018 and has since been headed by the NACR, held three consultations: in January 2018 and February 2019 for the CRs and the ChCR, and in March 2019 for the cantons, medical societies and the Federal Statistical Office.

The structure of the basic and supplementary variables is thus based on a broad national consensus, international recommendations,[3] the principles of good statistical and epidemiological practice, and legal requirements. It takes account of the fact that these data must be used for regular evaluations and publications at national level. The reasons for including a variable are stated. The registered data are forwarded to the NACR once a year in pseudonymised form. A distinction is drawn in the data structure between data that have to be registered at cantonal level and those that have to be submitted to the NACR.

Under the CRA, the registration of data that go beyond the mandatory national dataset presented here is possible, provided a cantonal law allows it (Art. 32 para. 4 CRA).

The National Cancer Data Dictionary comprises the following:

- This **Description of the legally binding data dictionary.**
- Part A: **Basic variables** (see Appendix).
- Part B1: **Supplementary variables adults** (see Appendix).
- Part B2: **Supplementary variables children and adolescents** (see Appendix).
- Part C: **Shortlist of all reportable clinical variables** (see Appendix).

The basic dataset

The basic dataset follows the provisions set out under Art. 3 CRA and Art. 1 and Art. 2 CRO. The aim of the mandatory basic variables is to ensure that the necessary data are collected nationwide in a complete and exhaustive manner to enable population-level monitoring of cancer. The basic variables are primarily used to monitor the development of cancers, to develop prevention and screening measures and to evaluate the quality of care, diagnosis and treatment. The data can also provide insights for cantonal planning for public health resources.
Basic variables should be reported for adults, children and adolescents from the time of diagnosis through to completion of the first treatment complex. In addition, the first recurrence of the disease is reportable.

Basic variable table

BASIC VARIABLES	**Adults**	**Children/ adolescents**
Patient data		
Personal identifiers	√	√
Data on the reporting persons and institutions		
Information to identify the reporting person or institution	√	√
Diagnostic data on cancer case		

[3] European Network of Cancer Registries (ENCR), International Agency for Research on Cancer (IARC), International Association of Cancer Registries (IACR), World Health Organization (WHO) etc.

Date of informing the patient	√	√
Date and type of cancer, type and characteristics of tumour	√	√
Tumour spread at the time of diagnosis, stage of disease	√	√
Diagnostic method and method of first detection	√	√
Tumour-related prognostic factors	√	√
Data on first treatment (first treatment complex)		
Type and goal for each treatment	√	√
Basis of treatment decision (once for the entire first treatment complex)	√	√
Start date of each treatment	√	√
Treatment-related prognostic factors (once for the entire first treatment complex)	√	√
Data on course of disease		
Date of diagnosis and localisation of metastases and other recurrences	√	√

Explanatory notes on basic variables

Patient data: Cancer registries must be able to electronically match personal data with population register data for the relevant canton. This prevents multiple registrations and allows vital status to be periodically updated.

Data on reporting persons and institutions: The information necessary to contact the reporting person or institution must be submitted so that the cancer registry can make enquiries if necessary. The CRA contains a provision (Art. 27) which provides for the possibility that cancer registration data may also be used to evaluate the quality of diagnosis and treatment. However, these data may only be disclosed and processed if the reporting person or institution has expressly consented to the disclosure of data with which they can be identified.

Diagnostic data on cancer: The date when the patient was informed must be documented as patients can veto registration and storage of their data. There is a three-month waiting period before the case can be registered. Even after the registration has been carried out, patients can request anonymisation of their data at any time. The tumour spread and stage of the disease at the time of diagnosis are recorded in detail. Among other things, this allows progress in screening to be documented. The method of first detection and diagnostic methods document the event that led to detection of the disease and the diagnostic methods used. Tumour-specific prognostic factors are included to adjust evaluations.

Data on first treatment (first treatment complex): The only basic variables that have to be reported are those that are necessary for regular analyses of the type and goal of the first treatment and that provide information on the basis of the treatment decision. The first treatment complex consists of all treatments planned after the diagnosis. These data allow conclusions to be drawn on the effectiveness and quality of treatments under everyday conditions (as opposed to the standardised conditions in clinical trials). They also allow equality of access to treatment and support services to be assessed, and quality of care to be monitored.

Data on course of disease: Information on the date and location of a subsequent occurrence of metastases or other recurrences allow the calculation of event-free survival, which is an important criterion in gauging the success of treatment.

The supplementary datasets by age group

The supplementary dataset follows the provisions set out under Art. 4 CRA and Art. 3 and Art. 4 CRO. Mandatory supplementary variables are collected to analyse additional questions for certain cancers and certain patient groups, depending on health policy requirements. A current priority involves improving coordinated care for patient groups who use many different and costly health services. The primary focus is on the patient group of older and very old people with multimorbidity.[4] The supplementary variables in adults for three types of tumour were defined by a working group consisting of various specialist medical organisations (FMH, SGMO, SGPatho, SGR-SSR), all members of Oncosuisse[5] and representatives of the federal government and cancer registries. The supplementary variables for children and adolescents were substantiated by the ChCR, together with representatives of the SPOG and the federal government. More extensive supplementary data are collected for children and adolescents than for adults. For adults, supplementary data must be reported up to completion of the first treatment complex. For children and adolescents, the data must be reported until recovery or death (information on follow-up examinations also have to be reported after recovery).

Supplementary variable table

SUPPLEMENTARY VARIABLES	Adults	Children/adolescents
Data on predispositions, prior diseases and comorbidities		
Predispositions	(√)	√
Prior diseases and comorbidities	(√)	√
Data on subsequent treatments		
Outcome of first treatment for each treatment measure		√
Type of subsequent treatments and treatment goals		√
Basis of treatment decision for each subsequent treatment		√
Start date of each subsequent treatment		√
Outcome of each subsequent treatment		√
Follow-up		
Information on follow-up examinations		√

(√): only for malignant breast, prostate or colorectal cancer

Explanatory notes on supplementary variables

Data on predispositions, prior diseases and comorbidities: These include patient-specific prognostic factors. In terms of supplementary variables for adults, in the coming years the focus will be on multimorbidity. These data must only be reported for the three most common types of cancer initially (breast, prostate and colorectal cancer). For children and adolescents, these data must be reported for all reportable cancers.

[4] Federal Office of Public Health, Health Policy Directorate, National Health Policy Section. https://www.g2020-info.admin.ch/ (German and French only) Keyword "koordinierte Versorgung" (coordinated care)

[5] The Swiss Federation against Cancer, Oncosuisse, is an association of seven Swiss organisations that is dedicated to beating cancer.

Data on subsequent treatments: Only for children and adolescents is the entire course of disease and treatment as well as all treatment outcomes recorded, including diseases occurring as a result of cancer treatment. In addition, prognostic or predictive cytogenetic markers are recorded.

Follow-up: Information on follow-up examinations is restricted to children and adolescents as some late effects may only appear decades after a cancer is cured.

Cancer registration handbook

As well as the National Cancer Data Dictionary, the NACR provides coding guidelines. These are usually based on existing national and international standards.[3] Where necessary, it supplements these with additional requirements which are decided in collaboration with the cantonal cancer registries, the Childhood Cancer Registry and the medical societies.

Development of the data structure

Registration practice is constantly updated to reflect the latest scientific findings in cancer epidemiology. The structure of the data is regularly reviewed and adapted to current health policy issues to provide the basis for timely health reporting. In order to fulfil the requirements and accommodate the financial means of the various institutions that participate in cancer registration and health reporting, the NACR involves the Federal Office of Public Health (FOPH), the cantons, the cantonal cancer registries, the Swiss Childhood Cancer Registry and the medical societies in defining and updating the data structure for supplementary variables. In addition, the CRA is periodically evaluated, for the first time at the latest five years after entry into force (Art. 34 CRA), i.e. on 1 January 2025.

Appendix

Overview of the National Data Dictionary outlining the data structure for cancer registration under CRA/CRO (2019)

Title	Content/ purpose	Format	Languages
Part A: Basic variables for adults, adolescents, and children	Defines cancer cases that need to be registered. Lists all variables in the basic dataset, along with their formats and coding. Variables are defined, justified and referenced where necessary. Explains which variables should be submitted to NACR.	pdf	EN, GE, FR, IT[6]
Part B1: Supplementary variables adults	Defines the cancer cases that need to be registered. Lists all variables in the supplementary dataset for adults, along with their formats and coding. Variables are defined, justified and referenced where necessary. Explains which variables should be submitted to NACR.	pdf	EN, GE, FR, IT[6]
Part B2: Supplementary variables children and adolescents	Defines the cancer cases that need to be registered. Lists all variables in the supplementary dataset for children and adolescents, along with their formats and coding. Variables are defined, justified and referenced where necessary.	pdf	EN, GE, FR, IT[6]
Part C: Shortlist of all reportable clinical variables	Lists all variable names in accordance with Table 1 of the explanations in the Federal Ordinance on the Registration of Cancerous Diseases (Cancer Registration Ordinance, CRO).	pdf	EN, GE, FR, IT[6]

Further information on cancer registration and information documents for cantonal authorities and reporting persons and institutions can be found on the FOPH website www.bag.admin.ch/bag/de/home/gesetze-und-bewilligungen/gesetzgebung/gesetzgebung-mensch-gesundheit/krebsregistrierung

[6] Translations into German (GE), French (FR), and Italian (IT) will be available before December 2019.