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

Concept for analysing cancer registry data

Version 1.0

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List of abbreviations

Acronym	Description of the
aDQR	Swiss annual Data Quality Report
ChCR	Childhood Cancer Registry
CCR	Cantonal Cancer Registries
CRA	Federal Act on the Registration of Cancerous Diseases
CRO	Cancer Registration Ordinance
DKG	Deutsche Krebsgesellschaft (German Cancer Society)
ECIS	European Cancer Information System
ENCR	European Network of Cancer Registries
FOPH	Federal Office of Public Health
FSO	Federal Statistical Office
HPV	Human Papilloma Virus
HRA	Human Research Act
HRC	Health Report on Cancer
ICD	International Classification of Diseases
NCD	National Cancer Dataset
NICER	National Institute for Cancer Epidemiology and Registration
NACR	National Agency for Cancer Registration
TNM	TNM Classification of Malignant Tumours
UICC	Union for International Cancer Control

1 Introduction

1.1 Overview

This "Concept for analysing cancer registry data" provides an overview of the various areas of analysis of national cancer registry data. These areas are based on the purposes defined in Article 2 of the Federal Act on the Registration of Cancerous Diseases (CRA) (1):

Art. 2 Purpose

This law is intended to create the necessary data basis to:

- a. monitor the development of diseases in accordance with Article 1;
- b. develop and implement prevention and screening programmes and assess their effectiveness;
- c. evaluate the quality of care, diagnosis and treatment;
- d. support care planning and research.

The "Concept for analysing cancer registry data" outlines the analyses of cancer registry data that are currently being conducted and those planned for the future, as well as why these are important. It addresses the overarching questions: "What is cancer registry data used for?" and "How can cancer registry data contribute to improving the health care of cancer patients and reduce the overall burden of cancer?". For patient awareness, it is crucial to transparently explain the purposes for which the data collected about their disease is used. For healthcare professionals and researchers, but also for interested members of the public, it is important to show where, to what extent and how regularly they can obtain up-to-date information on cancer development in Switzerland.

This concept focuses on national-level analyses of adult cancer cases conducted by the National Agency for Cancer Registration (NACR) and is based on the concept for the evaluation and publication of cancer data of the Federal Office of Public Health (FOPH) (2). For clarity, the areas of analysis and publication that are primarily carried out by the Federal Statistical Office (FSO) or the Childhood Cancer Registry (ChCR) are also described. In addition, the cantonal cancer registries (CCR) and the ChCR also carry out analyses, such as annual reports of the cancer registries, studies in cooperation with other institutions or analyses of specific indicators with their respective datasets. The analyses of the CCR and ChCR are not discussed in detail in this concept. Further information can be found on the website of the respective cancer registry.

1.2 Background

1.2.1 Development of cancer registration and introduction of the Federal Act on the Registration of Cancerous Diseases

The registration of cancer cases of adults is organised at a cantonal level in Switzerland and takes place in the CCR. In some cases, several cantons have joined together to form a regional cancer registry. The CCR continuously record all new cancer cases diagnosed in adult residents of each respective canton if there is no opposition of the patient. The notifiable cancers are defined in Annex 1 of the Cancer Registration Ordinance (CRO). Cases of children and adolescents up to the age of 20 are registered in the national ChCR. Each registry has its own institutional structure and works closely with hospitals, pathological laboratories and other entities that can provide information on cancer cases. The cantonal resident registers and the Central Compensation Office are also consulted in order to

regularly check whether patients are still alive or have died. The data on cancer cases of children and adolescents collected in the ChCR is forwarded annually to the responsible CCR. The CCR afterwards send the whole cantonal data to NACR, where it is merged into the National Cancer Dataset (NCD). The historical development of cancer registration in Switzerland, in particular the introduction of the CRA in 2020, is important for the evaluation of cancer registry data. Data in CCR date back to 1970. The ChCR was founded in 1976.

Before the CRA came into force, the analyses focused on the classic epidemiological indicators of cancer surveillance, which were published in the standard cancer monitoring (see Chapter 3). In addition, information on the type of tumour and was collected. However, there are gaps in the treatment data (e.g. systemic therapies) and data on precancerous lesions before 2020, as data collection mainly focussed on malignant tumours. Moreover, not every canton had a cancer registry and the start of data registration in the cantons varies (see Figure 1). The NCD consists of data before and after the introduction of the CRA. Consequently, the extent of data collection and the national coverage of cancer data for adults was less consistent and comprehensive before the CRA came into force.

Kantonale Krebsregister: Beginn der Datenerhebung
 Registres cantonaux des tumeurs: début de l'enregistrement des données

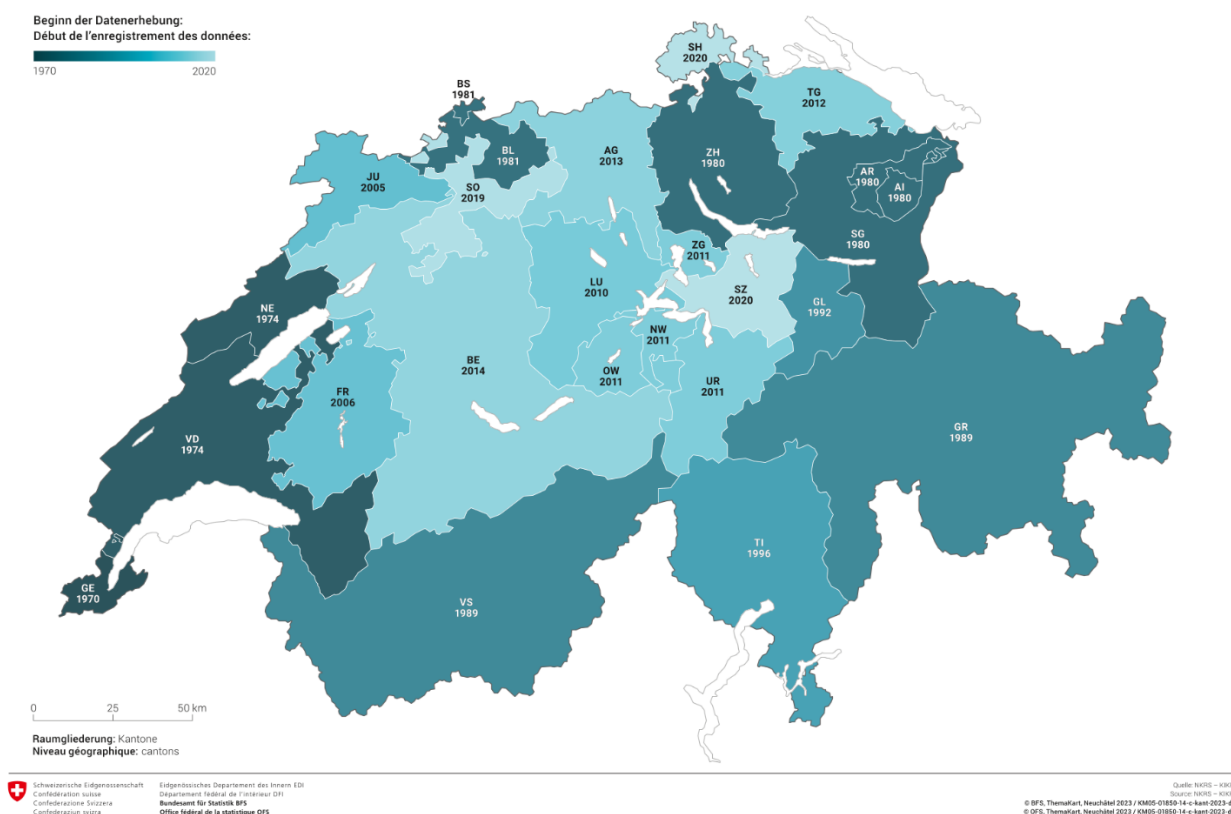


Illustration 1: Cantonal cancer registries: start of data registration (3)

In March 2016, the parliament passed the Federal Act on the Registration of Cancerous Diseases (CRA; SR 818.33) (1). In April 2018, the Federal Council adopted the associated ordinance (CRO; SR 818.331) (4). The CRA regulates the collection of meaningful and reliable data on cancer cases in Switzerland. It introduces a number of innovations such as mandatory reporting of defined cancer types, the use of the insurance number (OASI number) as a personal identifier and standardisation of the data record,

registration and data transmission. The CRA also contains regulations on patient rights and data protection. Since 1 January 2020, doctors, hospitals, private and public healthcare institutions that diagnose or treat cancerous diseases are obliged to report defined information on specified types of tumours to the responsible cancer registry. Prior to the introduction of the law, the information had to be collected by the cancer registries themselves from doctors, laboratories, and other sources. Based on the CRA and the CRO, a comprehensive and harmonised data basis is now being created in Switzerland that not only makes it possible to monitor the development of cancer, but also to develop and implement prevention and screening measures and review their effectiveness, to evaluate the quality of care, diagnosis and treatment, and to support care planning and research (Art. 2, CRA). In addition to malignant tumours, precancerous lesions and some benign tumours must also be reported in accordance with Annex 1, CRO. The scope of notifiable diseases varies according to age, with more diseases to be reported for children and adolescents under the age of 20.

NACR checks the quality and processes the data forwarded by the CCR in such a way that the data can be used for the above-mentioned analyses. In addition, the NACR regularly forwards the processed anonymised individual case data to the Federal Statistical Office (FSO) for statistical analyses, e.g. for the annual cancer monitoring (Art. 15, CRA) and the Swiss Cancer Report, which is published every five years. Together with the ChCR, the NACR is also responsible for the Health Report on cancer (HRC) in accordance with Art. 16, CRA. The aim of the HRC is to analyse cancer registry data in order to answer current health policy questions on the subject of cancer and to formulate recommendations for clinical practice, research and health policy (5). In addition to cancer monitoring and the cancer reports, NACR, ChCR, and the CCRs are authorised to process and publish cancer registry data for their own research initiatives (such as assessing the quality of diagnosis and treatment) and to support other research projects by making the data available in anonymised form (Art. 23, 27, CRA). The NACR publishes statistical results annually and on request (Art. 16, CRA). The basis for all analyses is the mandatory information on cancer cases that must be reported in accordance with Art. 3 and 4. The variables for this information are specified in the National Cancer Data Dictionary and are defined by the NACR (Art. 24-25, CRA). The National Cancer Data Dictionary is described in Chapter 2.2.

1.2.2 Potential of cancer registration and cancer registry data

An important goal of cancer registration is that cancer registry data is routinely analysed and used, so that the knowledge gained contributes to improving the patient care and health of the Swiss population. The standardised nationwide collected information on diagnosis, spread of the tumour, treatment and disease progression, can provide important population-based insights into the care, diagnosis and treatment of patients with cancer. Evidence-based analyses in these areas, as defined by the CRA, should therefore be established progressively. When selecting possible analyses, it is important to consider the potential, but also the special characteristics of the cancer registry data.

The potential of cancer registry data lies in the complete and comprehensive collection of reportable tumours and reportable information defined in the CRA, CRO and National Cancer Data Dictionary. This nationwide data collection, which is based on standards, enables reliable statements to be made on the cancer burden in Switzerland and facilitates comparisons across different geographic regions and demographic groups.

The orientation towards international recommendations and classification systems (e.g. recommendations of the European Network of Cancer Registries (ENCR), TNM classification, ICD-O-3 and ICD-10) ensures the national and international comparability of the data. This is particularly

important for international studies, the global exchange of information and comparing the development of cancer in Switzerland with cancer trends in other countries.

Cancer registry data provides "real world data", which means data that enables the quality and effectiveness of therapies to be observed and assessed under everyday conditions. This provides valuable insights into the actual use and effectiveness of treatments outside of controlled clinical trials. Cancer registry data is not selective because it includes the entire population. Moreover, cancer registry data is available for long periods of time, for some cantons going back decades, and offers high case numbers, which increases the significance of analyses. Cancer registry data also enables an assessment and monitoring of the quality of diagnosis and treatment independent of the care providers, which is in contrast to clinical studies that are usually limited to specific institutions and patient groups.

There are a few important points to keep in mind when using cancer registry data. For tumours diagnosed before the introduction of the CRA and CRO in 2020, complete information may not always be available. The reporting of information on tumour diseases prior to the introduction of the CRA was not required by a national law, which is why there are data gaps in terms of completeness, comprehensiveness as well as data harmonisation and standardisation throughout Switzerland. Moreover, precancerous lesions were not systematically and uniformly recorded during this period.

The general process, from the reporting of the disease by healthcare providers to the cancer registries, through the collection, forwarding, and processing of data in the registries and the NACR, takes time. This means that the NCD is only completed about two years after the date of diagnosis. The reporting of treatment, which usually takes several months, is also awaited. By comparing the data with hospital lists of inpatient cancer patients and with the cause of death statistics, cases are also identified that have not yet been recorded. The publication of statistics with cancer registry data is therefore only available with some time delay, but the data is fairly complete and exhaustive.

Clinical questions, particularly in the area of treatment, can only be partially answered, as only the initial treatment complex is recorded for adult cancer cases. This means that, at present, epidemiological cancer registration in Switzerland is not designed to provide detailed information on all treatments throughout the entire course of the disease or on specific therapeutic approaches.

In order to make the occurrence of tumour diseases internationally comparable, so-called primary tumours are defined according to globally standardised rules. A primary tumour is usually the original or first tumour of a specific type in a person's body. Metastases or the recurrence of a tumour (relapse) are not counted as new tumour cases but are registered in the course of the disease of the primary tumour. Second primary cancers of a different type or organ compared to previously diagnosed cancers are registered as new cases (6). These primary tumours form the basis of most of the analyses.

Another special feature of the NCD is that no directly identifying information on patients and institutions are available. The data is pseudonymised before being forwarded to the NACR. For example, the name and address of the patients and care providers are recorded by the cancer registries but not forwarded to the NACR. All dates such as date of birth or date of diagnosis are only transmitted as month and year. As a result, feedback to specific care providers, if requested by them, or analyses of detailed regional clusters of cancer cases are only possible through the cancer registries but not through the NACR.

In summary, cancer registry data offers valuable opportunities for monitoring cancer trends, evaluating the status of care and treatment for cancer patients, and providing an important basis for health services research. The present concept is based on the legal situation and data collection for adults since the introduction of the CRA and includes data from before 2020 for specific analyses if the data quality allows this.

2 Basis for analyses

The following is mainly focussing on data of tumours of adult persons ≥ 20 years of age which the NACR receives by the CCR. Tumours in children and adolescents < 20 years of age are recorded by the ChCR and processed by the ChCR (analysis, publication of results, cooperation with international organisations). The ChCR will publish a concept for analysing data of the childhood cancer registry. The NACR only uses data on cancer cases in children and adolescents when conducting overall analyses, e.g. analyses that cover the entire population across all age groups.

2.1 Notifiable tumours

Hospitals, doctors, laboratories and other private or public healthcare institutions are obliged by the CRA to report information on tumour cases to the respective CCR. The cancerous diseases to be reported are defined in Annex 1 of the CRO (4) (see table 1 in the appendix). As this analysis concept focuses on tumours in adults, the tumours to be reported are briefly summarised below. There are further reportable tumours in children and adolescents (see table 1 in the appendix).

Notifiable tumours in adults:

- Malignant tumours (C00-C97), with the exception of basal cell carcinomas of the skin (C44)
- In-situ tumours (D00-D09), with the exception of in-situ carcinomas of the skin
- Neoplasms of uncertain or unknown behaviour (D37-D48), with the exception of monoclonal gammopathy of undetermined significance (MGUS)
- Benign neoplasms of the brain and other parts of the central nervous system (D33), meninges (D32) and pituitary gland (D35.2), with the exception of hormone-inactive pituitary microadenomas (< 10 mm)

2.2 National Cancer Data Dictionary

The information collected in cancer registration is defined in the National Cancer Data Dictionary. The NACR is responsible for defining the National Cancer Data Dictionary; the CCR, the ChCR, the FOPH, the FSO, the cantons and the medical societies are involved in the decision-making process (7). The structure of the basic and supplementary data is thus based on a broad national consensus and is oriented towards international recommendations to ensure international comparability, the principles of good statistical and epidemiological practice and the legal requirements. It takes account of the fact that the data is to be used for regular analyses and publications at national level. The reasons why and for what purpose a variable is included and why the data must be recorded by the cancer registries are shown in the National Cancer Data Dictionary. The first version of the National Cancer Data Dictionary according to the CRA and CRO was published in 2019 and is reviewed and

updated annually. The National Cancer Data Dictionary is available on the website of the NACR (<https://www.nkrs.ch/de/downloads?cat=6>).

The National Cancer Data Dictionary is structured as follows:

- Basic variables for adults, adolescents and children (Part A)
- Supplementary variables for adults (Part B1)
- Supplementary variables for children and adolescents (Part B2)
- Short list of all reportable clinical variables (Part C)

2.2.1 Basic variables for adults, adolescents and children (Part A)

The basic data follows the requirements of Art. 3 CRA and Art. 1 and 2 CRO. The basic data is intended to ensure that the data required for population-based monitoring of cancer is collected comprehensively, completely and exhaustively.

Basic data is primarily used for the statistical analyses of the incidence, prevalence, type of cancer, mortality, survival, the type of the initial treatment and the course of the disease. The basic data is also used, partly in addition to the supplementary variables, to evaluate the quality of care, diagnosis and treatment. It is also possible to further stratify the basic data according to age, sex, region and stage at diagnosis (Art. 24, CRO). Basic data must be reported for adults, children and adolescents from the time of diagnosis until completion of the initial treatment complex. As the disease progresses, the occurrence of metastases and recurrences and their localisation must also be reported (Art. 1, CRO)

Some examples of variables in the basic data set are listed below:

- 1.2 Sex
- 2.3.1 Date of incidence
- 2.6 Method of first detection
- 3.4 ICD-O Topography
- 4.5 cM
- 4.40 Pathological tumour size

2.2.2 Supplementary variables for adults (Part B1), supplementary variables for children and adolescents (Part B2)

The supplementary data follows the requirements of Art. 4, CRA and Art. 3, 4, CRO. Supplementary data is collected in order to investigate additional questions for certain cancers and certain groups of people, depending on the health policy requirements.

The definition of the supplementary data in adults for three tumour types was drafted by a working group consisting of various medical professional organisations (Swiss Medical Association (FMH), Swiss Society of Medical Oncology (SSMO), Swiss Society of Pathology (SSPath), Swiss Society of Radiology (SSR)), all members of Oncosuisse, as well as representatives of the federal government and the cancer registries.

The supplementary data for children and adolescents was specified by the ChCR together with representatives of the Swiss Paediatric Oncology Group and the Confederation. More comprehensive supplementary data is recorded for children and adolescents than for adults.

Supplementary data must be reported for adults for three types of cancer (breast, prostate and colorectal cancer). For children and adolescents, supplementary data must be reported for all tumours until cure or death (information on follow-up examinations must also be reported after cure).

Some examples of variables in the supplementary data set are listed below:

- 9.1 Inherited predisposition(s) (adults)
- 10.14 Charlson Index (adults)
- 9.6.1 Late effect date of diagnosis (children and adolescents)
- 12.1 Study patient (children and adolescents)
- 13.1.1 Date of remission status or clinical follow-up (children and adolescents)

2.3 Data quality

The significance of analyses depends on the quality of the data. An essential first component of the evaluation process is therefore the quality check of the data.

The NACR publishes information and evaluations on data quality. The New Data Quality Concept (8) provides an overview of the various areas of quality assurance. A report on data quality with results on various quality indicators is published annually (9). Both documents are available on the NACR website.

The coding of tumours in Switzerland is based on internationally used classification systems, e.g. International Classification of Diseases for Oncology (ICD-O-3); TNM classification (TNM); International Classification of Diseases (ICD-10), and is oriented towards international standards and recommendations in cancer registration. Since 2020, the NACR has provided the CCR and the ChCR with a Swiss cancer registration handbook containing rules for the standardised recording and coding of reportable cancers throughout Switzerland.

2.4 Statistical methods

An overview of the statistical methods used for cancer monitoring (incidence, mortality, prevalence, survival) is available on the NACR website (10). The other methods not described in the methods document correspond to scientifically established methods and are reported separately where applicable. Good epidemiological and statistical practice is ensured in the analyses and great importance is attached to the international comparability of the data in accordance with Art. 24, CRA.

Age standardisation is performed to ensure comparability in terms of location and time. The rules of the ENCR for defining primary tumours for reporting and recording tumours must also be taken into account in the statistical analysis (6). For analyses of tumours with a date of incidence before 2020, an extrapolation to the whole of the country is made in most cases, as not all tumours were recorded throughout Switzerland before the CRA came into force.

2.5 Data protection

The use and disclosure of data on request is strictly controlled in accordance with the CRA (Art. 5-7, 10, 12, 23, 25-29) and CRO (Art. 28-30) in order to ensure patient data protection. A document with the data use regulations is published on the NACR website. The statistical results and underlying data are published or made accessible in a manner that excludes any identification of individual persons or institutions as per Art. 16 para. 3, CRA. In addition, every person has the right to object to the

registration of their data (Art. 6, CRA). Particularly when handling non-anonymised patient health data, the CCRs and ChCR must comply with the Federal Act on Data Protection.

3 Foundations of the publication of cancer registry data

3.1 Annual cancer monitoring

Cancer monitoring comprises the annual, routine, standardised and objective observation of the development of cancer in Switzerland. The FSO is responsible for the calculation and publication of the data for cancer monitoring (11). Epidemiological cancer monitoring is crucial for identifying trends, understanding variations in cancer rates and outcomes, and determining risk factors. This information helps to establish effective screening strategies, inform public health planning and prioritize research efforts to reduce the overall cancer burden.

Overview of published indicators for monitoring:

- Incidence
 - Number of new cases by sex, age, language region
 - Rate of new cases (age-specific, crude, age-standardised using the European or world standard) by sex, age, language region
 - Median age
 - Cumulative risk from birth to the age of 70
 - Proportion of all cancers (compared to all cancers except non-melanotic skin cancer)
- Mortality (not based on cancer registry data, but on the cause of death statistics of the FSO)
 - Number of deaths by sex, age, language region
 - Rate of deaths (age-specific, crude, age-standardised using the European or world standard) by sex, age, language region
 - Median age
 - Cumulative risk from birth to the age of 70
 - Proportion of cancer types (compared to all cancer types)
 - Potential years of life lost before the age of 70
 - Proportion of potential years of life lost (compared to all potential years of life lost due to cancer before the age of 70)
- Survival (under development at the FSO, presently provided by NACR, download available on NACR website)
 - Age-specific and age-standardised cumulative observed and relative survival for 1, 5, 10, 15 years after cancer diagnosis by year of diagnosis, sex, age
- Prevalence (provided by NACR, download available on NACR website)
 - Estimated number of prevalent persons at specific reference date and future projections by years since diagnosis, age, sex
 - Estimated proportion of prevalent persons at specific reference date and future projections by years since diagnosis, age, sex

Analyses are available via interactive tables, Excel lists and graphics on the FSO (11) and the NACR website (12).

3.2 Swiss Cancer Report

The Swiss Cancer Report is published every five years in printed and in electronic form on the FSO website (13). Like for the annual cancer monitoring, the FSO has the main responsibility for compiling the Swiss Cancer Report. The NACR and the ChCR are co-publishers and support the FSO both in calculating selected indicators and in editing the texts. Since the last Swiss Cancer Report, the cancer monitoring has been expanded providing objective information on the situation and trends of cancer indicators data on over 25 cancer sites on the last 30 years. The Cancer Report complements the national cancer monitoring and also describes and classifies the development of cancer in Switzerland in terms of national and international findings from health research (e.g. risk factors) and provides an international comparison. The first cancer report with data after the implementation of the CRA is expected to be published end of 2026 or beginning of 2027 and will include cancer registry data for the incidence years up to and including 2022.

The last Swiss Cancer Report was published in 2021 and included the following analyses:

- Incidence
 - Number of new cancer cases
 - Proportion of all cancers
 - Crude, age-specific and standardised rates (European or world standard)
 - Median age at diagnosis
 - Lifetime risk and risk of developing or dying from cancer up to the age of 70
- Mortality
 - Number of cancer deaths
 - Proportion of all cancers
 - Crude, age-specific and standardised rates (European or world standard)
 - Median age at death
 - Lifetime risk and risk of dying from cancer by the age of 70
 - Potential years of life lost
- Survival
 - Absolute survival rates
 - Relative survival rates
 - (Depending on the relevance of individual cancer localisations: Calculation of survival rates after 1, 5 or 10 years)
- Prevalence
 - Estimated number of prevalent persons at specific reference date and future projections by years since diagnosis, age, sex (period prevalence)
 - Instalments
- Estimate of expected cases of illness and deaths for 2021
- Mean annual change in rates (crude rates, age-standardised rates)
- Regional and international comparisons

3.3 Health Report on Cancer

The Health Report on Cancer (HRC) is published jointly by the NACR and the ChCR every three years. The FSO and the FOPH support them as required. The topics of the HRC change with each publication and are adapted to health policy developments, current research issues and the cancer situation. In addition to observation and description, the HRC focuses on evaluating the results and developing potential recommendations for policymakers, healthcare professionals and researchers. The HRC 2024 is dedicated to the topic of second primary cancers and is available on the NACR and ChCR websites (5,14).

The exact selection of topics for the HRC in 2027 and 2030 has not yet been finalised. Some topics were proposed in the concept for evaluation and publication of cancer data of the Federal Office of Public Health in 2020 (2).

3.4 Publication of further statistical results and provision of non-published results

To complement the above-mentioned publications and analyses of cancer registry data as part of the FSO's national cancer statistics, NACR focuses on more targeted and detailed analyses of cancer registry data and publishes respective results on its website. In addition, NACR handles data requests from third parties following a standard procedure to meet CRA and CRO requirements. Similarly, the ChCR publishes and provides statistics on cancer in children and adolescents < 20 years.

The focus of NACR's analyses and the definition and development of indicators are based on the CRA and CRO but it is also guided by the analyses of cancer registries in other countries, previous enquiries from researchers and the interests of health policy. The indicators and the various thematic focuses are discussed in more detail in Chapter 4.

Some examples of indicators that have not yet been systematically analysed in Switzerland and are to be established in the coming years are:

- Analyses of incidence, mortality and survival
 - by UICC stages
 - for specific tumour types (i.e. outside the FSO reporting groups)
 - by certain age groups (e.g. under 50-year-olds, "oldest old" with increasing life expectancy (15)) (FSO: 5-year age groups)
 - for precancerous lesions (FSO: malignant tumours)
- Analyses of the complete prevalence of cancer

The NACR also carries out selected statistical analyses on request and makes the results available to federal authorities, care providers, researchers, private individuals and the media, for example.

3.5 Provision of data to researchers

In accordance with Art. 23 of the CRA, the NACR, the CCR, the ChCR and the FSO support research and make the data available in anonymised form for research purposes. Access to the NACR data by third parties can be requested via an official form available from the NACR. Guidelines for persons and institutions that request statistics or data from the NACR can be found in the data use regulations provided by the NACR on the website. Before individual case data is shared, the data is anonymised in accordance with Art. 23, CRA and Art. 30, CRO. Moreover, a detailed review of the request is carried out, in which the risk of re-identification is evaluated. According to Art. 23 para. 4, CRA the provisions

of the Human Research Act (HRA) of 30 September 2011 (SR 810.30) apply to the collection, use or processing of all other and non-anonymised health-related personal data for research purposes.

4 Thematic priorities based on the CRA

4.1 Indicators

Indicators are used to analyse cancer registry data. There are internationally established epidemiological indicators such as incidence, prevalence, survival and mortality for monitoring the development of cancerous diseases (16). For other aspects of the analysis of cancer registry data there are no internationally established standardised indicators. We present a set of indicators for analyses of cancer registry data in Switzerland. As a first step in the development of indicators, the NACR is guided by the concept for the evaluation and publication of cancer data developed by the FOPH in collaboration with the FSO, the NACR and the ChCR as part of the Federal Act on Cancer Registration of December 2020 (2). Through a comprehensive literature search, integration of established national and international guidelines, consultations with experts from the medical societies and through orientation towards quality assurance indicators (e.g. Deutsche Krebsgesellschaft (DKG)) and indicators already established in other countries, in particular Germany (17), a preselection of certain indicators is made. The orientation towards already established indicators offers the possibility to compare the data nationally and internationally.

Indicators are created for cancers in general and for specific tumour entities separately (e.g. breast cancer). The selection of indicators should not be regarded as definitive but should be orientated towards the development of cancer, the needs of cancer care and research and should evolve successively. Indicators for other tumour entities will also be added on an ongoing basis. The definitions of the indicators are published in separate documents on the NACR website. The following chapters provide a thematic overview of the areas that can be evaluated using the indicators. Indicators for the respective areas are listed as examples, if already defined. No indicators are defined for some areas, as these are very specific analyses that are only developed as required.

The following types of indicators are defined based on the CRA, Art. 2:

- Indicators for monitoring the development of cancer
- Indicators for the evaluation of prevention and screening measures
- Indicators for evaluating the quality of care, diagnosis and treatment

The defined indicators can be used for various analyses. For example, as a one-off or regular standardised evaluation with publication on the NACR, ChCR or FSO website or as part of the Swiss Cancer Report or the HRC. In addition, the indicators provide politicians, the population, researchers, clinicians, cancer registries, the FOPH and the FSO with an overview of what can be evaluated with cancer registry data at population level and also aim to encourage the cancer registry data to be used and analysed more extensively in order to support cancer research. Aims of the analyses are to create a basis for decision-making to strengthen prevention and screening, as well as to improve the care of cancer patients.

A selection of indicators will be analysed by the NACR at regular intervals and discussed in an appropriate form, e.g. in cooperation with the professional societies, and published in a user-friendly form (Art. 16, CRA).

4.1.1 Monitoring the development of cancer

Regular and standardised population-based monitoring of cancer is important, for example, to identify changes in the incidence of certain tumours (type and extent of cancer burden, temporal trend, regional distribution) and to evaluate the effectiveness of diagnosis, treatment and follow-up care (e.g. mortality, survival, use of different forms of treatment). Not only the national, but also the international comparison of indicators is valuable. In addition to the standard annual cancer monitoring and the cancer report published every five years, the cancer registry data can be used to analyse further parameters for monitoring cancer in Switzerland.

a. Standard statistics

The standard statistics include the calculation of incidence, prevalence, survival and mortality. For malignant tumours, they are published in the annual cancer monitoring or in the Swiss Cancer Report. Some tumours have so far been grouped together, so that an evaluation per specific tumour type is also of interest. If irregularities are identified in the standard statistics, these can be addressed and investigated in greater depth as part of specific analyses or new research projects.

- **Incidence:** The incidence describes the number of new cases that occur within a defined population group in a certain period of time. It is given as the absolute number of new cases per year or as a rate per 100,000 inhabitants per year. The incidence rate indicates the risk of developing cancer. The incidence rate can be used to make statements about both temporal developments (e.g. trends) and spatial distributions (e.g. regional differences).
 - Indicator: Incidence

- **Prevalence:** The prevalence of a particular cancer refers to the number of people within a defined population group who have been diagnosed with this type of cancer and who were still alive at the time of the survey. Prevalence is an important and useful measure of the burden of cancer in society. Prevalence allows an assessment of the extent and type of cancer burden in the population and can therefore provide important information for care planning.
 - Indicator: Prevalence

- **Survival:** Survival after a cancer diagnosis is an important indicator for assessing the quality of the healthcare system as a whole. In-depth insights can be gained through time series analyses or regional comparisons of survival rates within Switzerland or comparisons with survival statistics from other countries. Survival is calculated as the proportion of survivors (often referred to as the survival rate) at specific time points after the diagnosis of cancer. Different methods can be used (e.g. all-cause or cause-specific survival) and different survival times can be calculated such as age-specific and age-standardised cumulative observed and relative survival 1 year, 2 years, 5 years or 10 years after diagnosis. Generally, survival reflects the time difference between the date of diagnosis and the date of death. Another interesting calculation is the time between the diagnosis date and the occurrence of a new cancer-specific event such as a local recurrence or metastasis. This is known as event-free survival. The different survival rates are important indicators for assessing the effectiveness of diagnosis, treatment and follow-up care for cancer.
 - Indicator: Survival

- **Mortality:** Mortality is the number of deaths within a defined population group in a given period. It can be expressed as an absolute number of deaths per year or as a rate per 100,000 inhabitants per year. The mortality rate measures the risk of dying from cancer. The mortality statistics are based on information from the civil registry offices and the doctors who report the deaths (deaths certificates). The coding of deaths and the determination of the underlying cause of death (underlying disease) is carried out by the FSO. The calculation of mortality is therefore based on data from the FSO's cause of death statistics. By analysing the annual cancer mortality rate and comparing it with previous years, it is possible to draw conclusions about the increase or decrease in cancer mortality in the population. This can, for example, provide information on the effectiveness of prevention and screening measures.

- Indicator: Mortality

b. Prognoses for the development of cancer

Established methods can be used to make predictions about the development of cancer using estimates. These predictions into the future are possible, for example, for incidence, i.e. the expected number of new cancer cases, and for prevalence, i.e. the expected cancer burden in society for a certain period of time. These forecasts can be helpful for care planning.

- Indicators: Predictions for incidence, mortality and prevalence

c. Tumour stages

At diagnosis, most tumours are classified into stages according to the Union for International Cancer Control (UICC). This staging is based on the TNM classification (18). There are other specific classification or staging systems for some tumours. The stage of the tumour disease is crucial for patients, as it is an important prognostic factor. The tumour stage is also essential for planning treatment. Apart from the high significance that the tumour stage has for the individual patient, it is also of great importance for epidemiological, (health) policy and medical issues. For example, the introduction of a screening programme may show that tumours are detected earlier, i.e. at lower stages, than it was previously the case. In addition, the stage-specific survival time or survival rate after 1, 5 and 10 years can be analysed.

- Indicator: Stage distribution at diagnosis

d. Therapies

Irrespective of the evaluation of the quality of treatment, it is of interest to provide a clear overview of the different forms of treatment for tumours. A breakdown into surgical therapy, chemotherapy, radiotherapy, immunotherapy, targeted therapy and hormone therapy reflects the forms of treatment at population level and can, for example, identify regional differences. They can also help to recognise usage patterns and trends either over time or regionally and thus provide information for care planning. It should be noted that in other countries there has already been a development from purely epidemiological to clinical cancer registries. This enables more in-depth recording of treatment data. In Switzerland, where population-based (epidemiological) cancer registration is established, less treatment data is collected compared to clinical cancer registries. Only the type of surgery is currently recorded in detail in Switzerland, whereas in the case of targeted therapies, for example, only the group of antibodies but not the drug itself is recorded. Cancer registration in

Switzerland is based on the international recommendations for recording treatment data from the European Network of Cancer Registries (ENCR). These ENCR recommendations are currently (as at the end of 2024) being revised.

- Indicators: Surgical treatment, radiotherapy, chemotherapy, hormone therapy, immunotherapy, targeted therapy, neoadjuvant treatment

e. Individual and rare tumours

In previous evaluations, different tumours were usually combined into groups, so-called "reporting groups". This means, for example, that tumours of the large intestine (colon; C18), rectosigmoid (C19) and rectum (C20) are evaluated together as the group "colorectal cancer". A separate evaluation of incidence, mortality, survival and prevalence of the specific localisations, of rare tumours and of very specific tumour types (e.g. small cell lung cancer), offers the possibility of being able to observe developments in individual tumour types in more detail and to recognising irregularities in the trends.

- Indicators: Tumour specific. E.g. colon and rectum separately.

f. Precancerous lesions and benign tumours

According to the CRO, not only malignant tumours are recorded, but also selected benign tumours (e.g. brain tumours), precancerous lesions and tumours with unclear behaviour. This data has not yet been systematically analysed. In international comparison, there have been few analyses at population level. Observing the frequency of precancerous stages, also in comparison to invasive tumours, can provide information of earlier detection of tumours in the context of organised or opportunistic screening examinations. The evaluation of precancerous lesions is therefore of particular interest for tumours for which screening is possible (e.g. breast cancer, colorectal cancer, cervical cancer, prostate cancer, bladder cancer, lung cancer).

Brain tumours are recorded regardless of their behaviour because both benign and malignant tumours can lead to severe clinical symptoms, some tumours can develop into malignant tumours in the course of time and benign tumours often cannot be primarily distinguished from malignant tumours on the basis of symptoms (19). The evaluation of all types of tumours is therefore relevant for brain tumours.

Precancerous lesions are also frequently integrated into the reporting for urothelial tumours. These are analysed based on the recommendations of the ENCR, as precancerous lesions often show progression over the course of the disease (20).

- Indicators: Tumour-specific. E.g. incidence D05 (in-situ carcinoma of the breast), proportion of precancerous lesions (proportion of in-situ carcinoma of the breast in all breast tumour cases), proportion of invasive breast cancer in patients with previous precancerous lesions

g. Regional distribution

An evaluation of different regional distributions at the level of municipality, canton, major regions, language regions, rural-urban or Switzerland as a whole is important for analysing regionally limited developments. The CCR also record the addresses and, in some cases, the residential history of people suffering from cancer, so that analyses of cancer incidence in highly localised areas, so-called cluster analyses, are possible. The NACR can only carry out analyses at least at the municipal level, as it only

receives the city/municipality number but not the patient's residential address. The region refers to the place of residence of the person concerned at the time of diagnosis.

In particular, the categorisation of large regions has become increasingly established internationally. The statistical office of the European Union (Eurostat) has categorised the countries of the European Union, the United Kingdom and EFTA into regions based on the criteria of the "Nomenclature of territorial units for statistics" (NUTS criteria) (21). This makes it easier to compare individual regions and small countries with larger countries on the basis of the regions. Switzerland is divided into seven major regions. Analysing incidence, mortality, survival and prevalence on the basis of these large regions offers the possibility of comparing similar regions with each other more effectively than is achieved by categorising them by canton or language region.

- Indicators: Incidence, mortality, survival, prevalence (each stratified by major region, language region, etc.)

h. Age distribution

Cancer is a disease that increases with age and, depending on the type of tumour, occurs more frequently in certain age groups. In Switzerland, the age at diagnosis is recorded in days. This allows different groups to be formed for analyses. A grouping in 5-year age groups is often used. For specific analyses, such as the analysis of screening examinations for breast cancer or colorectal cancer, other age groups are useful. If no age groups are formed, age standardisation is generally used to enable comparability in terms of location and time.

In Switzerland, standard analyses in the context of cancer reporting have so far ended with the age group ≥ 85 years. An extension of the age groups to 85-89 years, 90-94 years and ≥ 95 years to include the oldest old is currently the subject of much discussion due to increasing life expectancy and appears to make sense (15) if case numbers are sufficiently high.

- Indicators: Age at diagnosis, age at death, age at treatment, age at recurrence

i. Morphology

Different types of cancer have different shapes and structures of cancer cells or cancer cell clusters, which are referred to as morphology. Each specific type of tumour is assigned a specific morphology code according to ICD-O. A representation of the percentage distribution of the different morphologies of a tumour, such as small cell and non-small cell lung cancer over several years, can provide indications of possible causes or development trends.

- Indicators: Invasive breast cancer by morphology, preliminary stages of breast cancer by morphology

4.1.2 Evaluation of prevention and screening programme

Prevention measures and screening programmes play a crucial role in the fight against cancer, as they can make a decisive contribution to reducing the risk of developing the disease and improving the chances of recovery. In contrast to cancer registration, cancer prevention is regulated at the cantonal level. An organised screening for breast and bowel cancer has been established in many cantons. In addition, vaccination against human papillomavirus (HPV) is recommended nationwide by the FOPH

in order to reduce the development of HPV-associated tumours (22). Opportunistic screening is offered to prevent cervical cancer. Opportunistic screening activities are also widespread for prostate cancer (PSA measurement). For skin cancer prevention and screening, there are repeated campaigns that emphasise the importance of sun cream and regular skin checks. For lung tumours, organised screening for at-risk patients was recommended by a group of experts (23) and there is a pilot project in Vaud from 2023 (24). Organised screening is defined as a nationally or regionally organised screening programme with clear guidelines regarding various important aspects such as target population or diagnostic procedures. In the course of the organised screening, a targeted examination or search for an asymptomatic tumour is carried out. In contrast, opportunistic screening takes place outside of an organised or population-based screening programme; for example, on the basis of a recommendation from a healthcare professional that a woman has received during a routine medical examination or during a check-up, as there may be an increased risk of cervical cancer, for example (25).

According to the WHO, around 30% of all cancers can be prevented through preventive strategies (26). These include reducing alcohol consumption, not smoking, a healthy diet and vaccinations, particularly against HPV and hepatitis B. Screening programmes, organised at the cantonal level in Switzerland, are intended to help detect precancerous lesions or tumours early (e.g. mammography) or to prevent the development of a cancerous lesion (e.g. colonoscopy). Overall, screening programmes aim to prevent cancer or to improve treatment options and thus the chances of recovery through early diagnosis (27). This can be measured using various indicators, e.g. by comparing mortality rates or stage distribution in the different groups (28). Some indicators that can be evaluated with cancer registry data are listed below. More in-depth analyses of prevention and screening measures can be carried out as part of research projects and with the inclusion of other data sources and information.

a. Diagnosis through screening

In the National Cancer Data Dictionary, the variable "Method of first detection" records the method or circumstance by which a tumour was first noticed, and the cancer was first diagnosed. An evaluation of this variable shows whether clinical symptoms, an incidental discovery, an organised or opportunistic screening or an autopsy led to the diagnosis of the cancer. The data can be further stratified by canton with or without an established screening programme.

- Indicators: Method of first detection, first detection in an organised screening programme

b. Stage distribution and precancerous lesions

The evaluation of the tumour stages at time of the initial diagnosis provides information on whether tumours are detected early or late. Depending on the type of tumour, patients show different symptoms. Some tumours remain asymptomatic for a long time, while others show symptoms at an early stage. A comparison of cantons with or patients diagnosed in screening programmes and cantons without or patients not diagnosed in screening programmes, as well as a comparison over time before and after the introduction of a screening programme, can be used to evaluate the effectiveness of these programmes. The comparison of tumour stages, the proportion of precancerous stages and incidence shifts can be used to evaluate whether tumours are detected earlier through screening programmes.

- Indicators: Incidence, stage distribution at diagnosis, proportion of precancerous lesions (proportion of in-situ carcinoma of the breast in all breast tumour cases)

c. Survival and mortality

One aim of screening programmes is to prolong the survival of cancer patients and reduce cancer mortality. By comparing the cancer-specific survival rates before and after the introduction of a screening programme, or of cantons with and without a screening programme, or of patients diagnosed in or patients not diagnosed in a screening programme, it is possible to evaluate whether this goal has been achieved. It is expected that survival is prolonged due to the larger fraction of patients with low-stage tumours. It is also important for patients to know whether general mortality and cancer mortality has been reduced by the programmes. The comparison of cancer mortality in different cantons with and without a screening programme and the comparison of tumours detected as part of a screening programme with tumours not detected as part of a screening programme within a canton make it possible to draw conclusions about the effectiveness of the programmes, and particularly the benefits for the population.

- Indicator: Survival after diagnosis as part of a screening programme (yes/no), mortality after diagnosis as part of a screening programme (yes/no)

d. Overdiagnosis and overtreatment

Although screening programmes have the potential to detect tumours at an early stage and thus improve treatment options and patient survival, they also have potential disadvantages. If tumours are detected that would not have led to health restrictions or death of the patient throughout their life, this is referred to as overdiagnosis. Overdiagnosis may also result in overtreatment (29). The therapies can in turn lead to severe side effects and reduce the patient's quality of life. In addition, overdiagnosis and overtreatment are also relevant in terms of health policy, as they lead to additional costs in the healthcare system (29). One way of examining overdiagnosis and overtreatment is to compare the incidence and mortality rates of populations with and without a screening programme or to compare patients with different methods of first detection (incidental discovery, clinical symptoms, organised screening, opportunistic screening, self-examination, death). However, to compare population groups with observational/cancer registry data, additional factors such as the distribution of risk factors, different health awareness and behaviour, or the screening participation rate have to be taken into account (28). Another method to analyse overdiagnosis is to assess the time trends in cancer incidence and stages. In theory, following the introduction screening, the incidence of cancers initially increases and, after a few years return to the pre-screening level. In case of overdiagnosis, the incidence remains above the pre-screening level (28).

- Indicators: Not yet defined; specific analysis depending on the need

e. Time course

Certain legislative changes or the development of new measures to prevent cancer are interesting for analysing changes in cancer incidence over time and assessing the impact of the measures taken.

In Switzerland, smoking has been banned in enclosed spaces such as offices, restaurants and schools since 2010. The primary aim of the prohibition is to protect the population from passive smoking. Not only direct smoking, but also passive smoking poses a threat to health and is a risk factor for serious

illnesses such as cancer and cardiovascular diseases (30). By reducing the population's exposure to passive smoking, a long-term decrease in the incidence of lung cancer could be expected if the smoking behaviour of the population (active smokers) remains the same or even drops further. It is therefore interesting to observe the incidence over time and to take into account the trends in the smoking behaviour for the analyses.

Infections with human papillomaviruses (HPV) are among the most common sexually transmitted infections and can lead to various cancers in men and women, in particular cervical cancer or tumours in the throat area. There are different types of HPV. There is a vaccination against some types, which has been recommended by the FOPH for girls since 2008 and for boys since 2015. Vaccination can prevent infections and subsequently cancers, which in the long term should be reflected in a reduction in the incidence of HPV-associated tumours (31).

- Indicators: Not yet defined; specific analysis depending on the question and tumour type

4.1.3 Evaluation of the quality of care

Healthcare refers to the access and availability of medical services for individuals or population groups. Good and effective healthcare for people with cancer must fulfil several criteria: It must be effective, ensure patient safety, tailor its services to the individual needs and wishes of patients, be timely, appropriate and delivered in a coordinated manner (32). Some of these criteria can be evaluated with cancer registry data.

a. Time between diagnosis and start of treatment

Timeliness and availability can be analysed by evaluating the time between diagnosis and start of treatment, e.g. date of surgery. Studies have shown that in breast cancer, the length of the interval between diagnosis and surgery correlates negatively with the survival (33).

- Indicators: Time between diagnosis and start of treatment, time between diagnosis and surgical treatment

b. Discussion in interdisciplinary tumour boards

In internationally established guidelines for the diagnosis and treatment of tumours, it is almost always recommended that tumour cases are discussed in multidisciplinary tumour boards in order to determine the best possible and quality-assured treatment for patients. In the National Cancer Data Dictionary, the variable "Basis of first treatment complex decision" records if a patient's treatment was discussed in a tumour board or not. This makes it possible to evaluate whether patients receive optimal care and whether a multidisciplinary exchange for treatment planning is taking place in a tumour board.

- Indicator: Treatment decision at a tumour board

c. Regional differences

For each cancer, the cancer registry records the patient's place of residence at the time of diagnosis. This enables regional evaluations such as urban and rural regions or distance to/region with or without a specialised tumour centres. By comparing the incidence of specific cancers or the survival of cancer

patients in different regions, important information can be generated for healthcare research. For example, low survival rates in certain regions could indicate deficits in the quality of care, such as a lack of specialised treatment centres. The influence of the distance from the patient's place of residence to a specialised treatment centre on cancer treatment or survival can also be investigated using cancer registry data. Health authorities can use this information for their planning and thus improve the quality of care.

- Indicators: Incidence, survival (by region)

d. Socio-demographic differences

Healthcare in Switzerland is generally at a high level (34). Nevertheless, there are groups of people who are affected by underuse, overuse or inadequate care (35). Identifying these groups offers the opportunity to take measures to improve equality of opportunity in healthcare. Cancer registry data can be analysed by sex, age, nationality, civil status or region of residence. The linkage of registry data with the Swiss Neighbourhood Index of Socioeconomic Position (36) or other variables representing socioeconomic status enables also the identification of potential inequalities in the Swiss healthcare system. The comparison of, for example, tumour stages at diagnosis, the implementation of tumour boards or the time from diagnosis to the start of treatment for groups of people with different socio-demographic characteristics can therefore identify possible differences in access to healthcare in Switzerland.

- Indicators: Tumour stages at diagnosis; time between diagnosis and start of treatment; discussion in interdisciplinary tumour boards (each stratified by sex, age, region, nationality, civil status)

4.1.4 Evaluation of the quality of diagnosis and treatment

High diagnostic quality is characterised by timely, correct, precise and patient-centred diagnostics. Rapid recognition of the disease is of great prognostic importance, particularly in the case of cancer. The diagnosis of tumours is usually a step-by-step process and includes clinical examinations, imaging procedures, histopathological assessment and, if necessary, cytological, molecular and cytogenetic examinations. The diagnostic procedures that have yielded a positive result, i.e. the detection of a tumour, are recorded in the cancer registry.

The treatment of tumours is of great importance to patients. It often takes place in so-called tumour centres. These centres are regularly audited and receive certification by meeting defined criteria to ensure high quality (e.g. DKG certification).

There are also national and international guidelines with recommendations for the diagnosis and treatment of tumour diseases (e.g. S3 German guideline program in oncology (37)). Cancer registry data can be used to check compliance with certain treatment guidelines. However, it is important to note that in addition to the recommendations of the guidelines, many other factors, such as the patient's general state of health and/or the patient's desire for or against certain therapies, influence the choice of treatment.

Tumours are treated very specifically depending on the type and spread of the tumour. For this reason, many evaluations of treatment quality are specific to individual tumour types.

a. Histological confirmation of the diagnosis

One starting point for evaluating the quality of diagnosis with cancer registry data is to determine the proportion of cases with histological confirmation. The aim is to ensure that as many tumours as possible can be confirmed by histological examination if this is the gold standard for this type of tumour. According to ENCR, some tumours, such as certain neuroendocrine tumours or germ cell tumours, can also be diagnosed and recorded on the basis of tumour markers in combination with clinical symptoms, but in most cases histological confirmation is also performed (38). In addition to the diagnostic procedures used, the procedure with the highest diagnostic certainty (histology and cytogenetic or molecular examination) is also recorded in the cancer registry and can be used for evaluation.

- Indicator: Histological diagnosis confirmation

b. Resection status and resection margin after surgery

For solid tumours, the resection status after surgery is a decisive prognostic factor. It indicates whether a tumour (and any metastases) could be completely removed or not. If the tumour could be completely removed, patients generally have a longer survival than if the tumour could not be completely removed. In addition to the resection status, the resection margin is also recorded in cancer registration. The resection margin indicates the distance of the tumour to the edge of the surgically removed tissue. The resection margin is a tumour-specific prognostic factor for oral cavity cancer, breast cancer and other tumours (18). In addition to the pure representation of the distribution of the resection status and the characteristics of the resection margin for the respective tumour, the correlation with survival should also be examined as a further measuring instrument.

- Indicator: Resection status after surgery

c. Guideline-compliant therapy

Guidelines are tumour-specific, which is why different indicators must be defined depending on the type of cancer. Cancer registry data can be used to check compliance with selected guideline recommendations or the implementation of new guidelines in practice. Limiting factors for analyses are that only the initial treatment complex is available in cancer registration in Switzerland and that other factors, such as a patient's preference for a specific therapy or the decision to decline a treatment, are not recorded. The following are examples of guideline recommendations for the treatment of breast cancer that can be verified using cancer registry data. If, for example, the diagnosis of breast cancer shows that the tumour is hormone receptor-positive, hormone therapy is recommended as standard for invasive breast cancer. Similarly, invasive breast cancer is tested for overexpression or amplification of the HER2 receptor, in which case targeted therapy with antibodies is recommended to improve the prognosis (39). If the breast cancer can be surgically removed in such a way that the breast is preserved (breast-conserving therapy), radiotherapy is recommended following the operation.

- Indicators: Guideline-based therapy, tumour-specific. E.g. radiotherapy after breast-conserving therapy for breast cancer and precancerous lesions; chemotherapy for HER2-positive, node-positive breast cancer; hormone therapy for hormone-receptor-positive breast cancer; antibody therapy for HER2-positive breast cancer

d. Survival by treatment

Survival or the chances of survival are of immense importance for patients with cancer. Overall survival is defined as the time from diagnosis to death from any cause. The calculation of survival rates for different therapies provides an overview of the quality of treatment. However, the impact of different treatment regimens cannot be analysed in detail due to lack of extensive treatment data (e.g. drug name, dosage, end date, second line treatment). But for example, whether changes of treatment regimes in guidelines valid for Switzerland have led to changes in survival times or survival rates over time, could be evaluated.

Stratification according to other prognostic factors, such as the stage at initial diagnosis or the receptor status in breast cancer, is important in order to exclude possible confounding factors.

- Indicator: Survival (with further stratification depending on the research question)

e. Event-free survival by treatment

In addition to overall survival, event-free survival, which is defined as the time from diagnosis to the occurrence of progression, metachronous metastasis or local recurrence, is an important parameter for the quality of treatment. It provides information on the long-term effectiveness of the treatment.

- Indicator: Event-free survival (with further stratification depending on the research question)

f. Recurrence rate by treatment

The frequency with which a tumour recurs after a phase of remission or successful initial treatment is referred to as the recurrence rate. It is of great importance to patients, as it allows conclusions to be drawn about the prognosis. Cancer registration records information about the aim of the first treatment and about events during the course of the disease. This makes it possible to calculate the recurrence rate, e.g. after primary curative therapy.

- Indicator: New event in the course of the disease (progression, metastasis, recurrence) (with further stratification depending on the research question)

4.1.5 Support for health care resource planning

Cancer registration should and can support care planning. In particular, forecasts on the development of cancer cases at cantonal or national level, such as estimates of new cancer cases and the cancer burden in the population, are important parameters for planning appropriate care structures or adapting these on the basis of forecast needs (see also section 4.1.1 b. Prognoses for the development of cancer).

4.2 Support for research

Analyses with cancer registry data provide an overview of cancers at population level. They focus on the broadest and most comprehensive possible reporting on cancer and allow irregularities to be identified. For example, analyses can show spatial, temporal or cancer-specific trends that can be explored in greater depth in further research projects. Cancer registry data offer a variety of possible analyses for answering questions in a real-world setting in the field of cancer. Collaboration between cancer registries and researchers for in-depth analyses is therefore important for both sides.

In accordance with Article 23, CRA, the NACR, the CCR, the ChCR and the FSO shall support research. On request, they make the data under this act available in an anonymised form for research purposes. The transfer of data is checked and is subject to defined guidelines to ensure data security (see chapter 2.5 Data protection). The ChCR and the NACR can also use their own data for research purposes in accordance with the CRA.

4.3 Forwarding of data to international organisations

The NACR and ChCR can collaborate with foreign institutions and international organisations and make the anonymised data available to them. The NACR is responsible for the collaboration with international organisations for cancer registry data of adults, whereas the ChCR is responsible for the collaboration with international organisations for data of children and adolescents. As it is of great interest that Switzerland is represented in international studies, the NACR and the ChCR regularly provide the following studies and organisations with cancer registry data.

The CONCORD programme of the London School of Hygiene & Tropical Medicine uses the data provided to monitor trends in cancer survival rates in over 70 countries (40). Analysing the different survival rates also make it possible to compare different healthcare systems and their effectiveness in the treatment of cancer patients and thus also provides important insights for policymakers. Furthermore, the NACR and ChCR regularly provide cancer registry data to the Joint Research Centre (JRC) of the European Union and the European Network of Cancer Registries (ENCR) for updating the European Cancer Information System (ECIS) (41). The ChCR also participates in initiatives specialised on paediatric cancer, such as International Benchmarking of Childhood Cancer Survival by Stage (BENCHISTA) or Cancer Risk in Childhood Cancer Survivors (CRICCS). Cancer registry data from Switzerland is also included in WHO publications on cancer incidence (e.g. Cancer Incidence in five continents CI-5, International Agency for Research on Cancer).



5 Appendix

Table 1: The following diseases, according to the International Classification of Diseases by the WHO in its 2010 version (ICD-10), must be reported according to the CRO, Annex 1; the relevant criterion is the disease group defined by the three-digit code:

Code	Designation	Basic data for diagnosis / basic data for initial treatment		Additional data	
		Adults	Children and young people	Adults	Children and young people
C-CODES					
C00-C97	Malignant neoplasms	yes, except basal cell carcinoma (C44: 8090-8098)	yes, except basal cell carcinoma (C44: 8090-8098)	yes, for: Intestine (C18-C20) Breast (C50) Prostate (C61)	yes, except basal cell carcinoma (C44: 8090-8098)
D-CODES					
D00-D09	Carcinoma in situ				
D00	Carcinoma in situ of the oral cavity, oesophagus and stomach	Yes	Yes	no	Yes
D01	Carcinoma in situ of other and unspecified digestive organs	Yes	Yes	no	Yes
D02	Carcinoma in situ of the middle ear and respiratory system	Yes	Yes	no	Yes
D03	Melanoma in situ	Yes	Yes	no	Yes
D04	...				
D05	Carcinoma in situ of the mammary gland	Yes	Yes	no	Yes
D06	Carcinoma in situ of the cervix uteri	Yes	Yes	no	Yes
D07	Carcinoma in situ of other and unspecified genital organs	Yes	Yes	no	Yes
D09	Carcinoma in situ of other and unspecified localisations	Yes	Yes	no	Yes
D10-D36	Benign neoplasms				
D32	Benign neoplasms of the meninges	Yes	Yes	no	Yes
D33	Benign neoplasm of the brain and other parts of the central nervous system	Yes	Yes	no	Yes
D35	Benign neoplasm of other and unspecified endocrine glands	no	Yes	no	Yes
D35.2	Benign neoplasm of the pituitary gland	yes, except hormone-inactive pituitary microadenomas (< 10 mm)	yes, except hormone-inactive pituitary microadenomas (< 10 mm)	no	yes, except hormone-inactive pituitary microadenomas (< 10 mm)



Code	Designation	Basic data for diagnosis / basic data for initial treatment		Additional data	
		Adults	Children and young people	Adults	Children and young people
D37-D48	Neoplasms of uncertain or unknown behaviour				
D37	Neoplasm of uncertain or unknown behaviour of the oral cavity and digestive organs	Yes	Yes	no	Yes
D38	Neoplasm of uncertain or unknown behaviour of the middle ear, respiratory organs and intrathoracic organs	Yes	Yes	no	Yes
D39	Neoplasm of uncertain or unknown behaviour of the female genital organs	Yes	Yes	no	Yes
D40	Neoplasm of uncertain or unknown behaviour of the male genital organs	Yes	Yes	no	Yes
D41	Neoplasm of uncertain or unknown behaviour of the urinary organs	Yes	Yes	no	Yes
D42	Neoplasm of uncertain or unknown behaviour of the meninges	Yes	Yes	no	Yes
D43	Neoplasm of uncertain or unknown behaviour of the brain and central nervous system	Yes	Yes	no	Yes
D44	Neoplasm of uncertain or unknown behaviour of the endocrine glands, except pituitary gland	Yes	Yes	no	Yes
D45	Polycythaemia vera	Yes	Yes	no	Yes
D46	Myelodysplastic syndromes	Yes	Yes	no	Yes
D47	Other neoplasms of uncertain or unknown behaviour of the lymphatic, haematopoietic and related tissue	yes, except monoclonal gammopathy of undetermined significance (MGUS)	yes, except monoclonal gammopathy of undetermined significance (MGUS)	no	yes, except monoclonal gammopathy of undetermined significance (MGUS)
D48	Neoplasm of uncertain or unknown behaviour in other and unspecified locations	Yes	Yes	no	Yes
D61	Other aplastic anaemias	no	Yes	no	Yes
D76	Other specified diseases involving the lymphoreticular tissue and the reticulohistiocytic system	no	Yes	no	Yes

6 Bibliography

1. SR 818.33 - Bundesgesetz vom 18. März 2016 über die Registrierung von Krebserkrankungen (Krebsregistrierungsgesetz, KRG) [Internet]. [cited 2024 Mar 25]. Available from: <https://www.fedlex.admin.ch/eli/cc/2018/289/de>
2. Konzept für die Auswertung und Veröffentlichung von Krebsdaten im Rahmen des Bundesgesetzes über die Registrierung von Krebserkrankungen (Krebsregistrierungsgesetz, KRG) [Internet]. Version 1.0. Bern: Bundesamt für Gesundheit BAG; 2020 [cited 2023 Nov 16]. Available from: <http://www.bag.admin.ch/krge-datennutzung>
3. Kantonale Krebsregister: Beginn der Datenerhebung [Internet]. [cited 2024 Sep 30]. Available from: <https://www.bfs.admin.ch/asset/de/29845860>
4. SR 818.331 - Verordnung vom 11. April 2018 über die Registrierung von Krebserkrankungen (Krebsregistrierungsverordnung, KRV) [Internet]. [cited 2024 Mar 25]. Available from: https://www.fedlex.admin.ch/eli/cc/2018/290/de#annex_1
5. Nationale Krebsregistrierungsstelle (NKRS), Kinderkrebsregister (KiKR) L. Gesundheitsberichterstattung über Krebs 2024 Zweitumorrisiko [Internet]. [cited 2024 Dec 19]. Available from: https://www.nkrs.ch/upload/downloads/Berichte%20und%20Statistiken/GBE/Final/241209_Gesundheitsberichterstattung_2024.pdf
6. International Agency for Research on Cancer, World Health Organization, International Association of Cancer Registries, European Network of Cancer Registries. International rules for multiple primary cancers (ICD-O Third Edition) [Internet]. 2004 [cited 2024 Mar 25]. Available from: https://encr.eu/sites/default/files/pdf/MPrules_july2004.pdf
7. Nationale Krebsregistrierungsstelle, Kinderkrebsregister. Darstellung der für alle Krebsregister rechtlich verbindlichen Datenstruktur nach KRG/KRV [Internet]. 2019 [cited 2024 Mar 25]. Available from: <https://nkrs.ch/upload/downloads/Forschende/Datenstruktur/0-introduction-datadictionary-de-v1.1.pdf>
8. Lorez M, Feller A, Schmidt A, Wagner U. New Data Quality Concept [Internet]. [cited 2024 Jan 15]. Available from: <https://www.nkrs.ch/assets/files/uploads/nacr-data-quality-concept-v1.pdf>
9. National Agency for Cancer Registration. Swiss annual Data Quality Report (aDQR) 2022 [Internet]. 2023. Available from: <https://www.nkrs.ch/assets/files/uploads/final-executive-summary-29-sept-2023.pdf>
10. Abawi K, Feller A, Lorez M, Michalopoulou E, Roy E, Spycher B, et al. Statistical Methods for Cancer Reporting in Switzerland [Internet]. [cited 2024 Jan 15]. Available from: <https://www.nkrs.ch/assets/files/uploads/methodenbericht-final-20220617.pdf>
11. Bundesamt für Statistik. Krebs im Überblick [Internet]. [cited 2023 Dec 15]. Available from: <https://www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/gesundheitszustand/krankheiten/krebs.html>

12. NKRS [Internet]. [cited 2024 Sep 12]. Downloads und Links - Statistiken und Berichte (Krebsinzidenz, Krebsmortalität, Krebsprävalenz, Krebsüberleben). Available from: <https://www.nkrs.ch/de/downloads?cat=7>
13. Bundesamt für Statistik. Schweizerischer Krebsbericht 2021 - Stand und Entwicklungen | Publikation [Internet]. 2021 [cited 2023 Nov 15]. Available from: <https://www.bfs.admin.ch/asset/de/19305696>
14. Nationale Krebsregistrierungsstelle (NKRS), Kinderkrebsregister (KiKR). Childhood Cancer Registry (ChCR). [cited 2024 Dec 19]. Health reporting on cancer (HRC). Available from: <https://www.childhoodcancerregistry.ch/statistics-and-reports/health-reporting/>
15. Hashim D, Carioli G, Malvezzi M, Bertuccio P, Waxman S, Negri E, et al. Cancer mortality in the oldest old: a global overview. *Aging*. 2020 Sep 3;12(17):16744–58.
16. Jensen OM, International Agency for Research on Cancer, World Health Organization, International Association of Cancer Registries, editors. *Cancer registration: principles and methods*. Lyon, France : New York: International Agency for Research on Cancer; Distributed in the USA by Oxford University Press; 1991. 288 p. (IARC scientific publications).
17. Leitlinien Qualitätsindikatoren - Plattform § 65c - Confluence Instanz [Internet]. [cited 2023 Nov 15]. Available from: <https://plattform65c.atlassian.net/wiki/spaces/LLQI/overview?homepageId=100600511>
18. Brierley J, Gospodarowicz MK, Wittekind C, editors. *TNM classification of malignant tumours*. Eighth edition. Chichester, West Sussex, UK ; Hoboken, NJ: Wiley Blackwell; 2017. 253 p.
19. Draft recommendation on CNS tumours - consultation to the registries | European Network of Cancer Registries [Internet]. [cited 2024 Oct 4]. Available from: <https://encr.eu/news/draft-recommendation-cns-tumours-consultation-registries>
20. ENCR Working Group. ENCR Recommendations Recording and Reporting of Urothelial Tumours of the Urinary Tract [Internet]. [cited 2024 Oct 4]. Available from: https://encr.eu/sites/default/files/Recommendations/ENCR%20Recommendation_UT_Jun2022_EN.pdf
21. Maps - Eurostat [Internet]. [cited 2024 Apr 4]. Available from: <https://ec.europa.eu/eurostat/web/nuts/maps#expand-ch-1712212413528>
22. Bundesamt für Gesundheit. Schweizerischer Impfplan [Internet]. [cited 2024 Oct 4]. Available from: <https://www.bag.admin.ch/bag/de/home/gesund-leben/gesundheitsfoerderung-und-praevention/impfungen-prophylaxe/schweizerischer-impfplan.html>
23. Lungenkrebs-Screening mittels LDCT | Cancer Screening Committee [Internet]. 2019 [cited 2024 Oct 4]. Available from: <https://cancerscreeningcommittee.ch/themen/lungenkrebs-screening-mittels-ldct/>
24. The Pilot Project | Lung cancer screening - Canton of Vaud [Internet]. [cited 2024 Dec 5]. Available from: <https://www.depistagepoumon-vd.ch/le-projet-pilote>

25. IARC Working Group on the Evaluation of Cancer-Preventive Strategies. Cervical cancer screening. Lyon, France: International Agency for Research on Cancer; 2022. 1–456 p. (IARC handbooks of cancer prevention).
26. World Health Organization. Cancer. [cited 2024 Oct 4]. Cancer. Available from: <https://www.who.int/news-room/fact-sheets/detail/cancer>
27. Cancer - Screening and early detection [Internet]. [cited 2024 Oct 9]. Available from: <https://www.who.int/europe/news-room/fact-sheets/item/cancer-screening-and-early-detection-of-cancer>
28. Duffy SW, Smith RA. The Evaluation of Cancer Screening. *Med Clin North Am*. 2020 Nov;104(6):939–53.
29. Chiolero A, Paccaud F, Aujesky D, Santschi V, Rodondi N. How to prevent overdiagnosis. *Swiss Med Wkly*. 2015;145:w14060.
30. World Health Organization. Tobacco [Internet]. [cited 2024 Dec 19]. Available from: <https://www.who.int/news-room/fact-sheets/detail/tobacco>
31. Bundesamt für Gesundheit. Humane Papillomaviren (HPV) [Internet]. [cited 2024 Apr 22]. Available from: <https://www.bag.admin.ch/bag/de/home/krankheiten/krankheiten-im-ueberblick/hpv.html>
32. Was verstehen wir unter guter Versorgungsqualität? [Internet]. [cited 2024 Apr 4]. Available from: <https://iqtig.org/das-iqtig/rahmenbedingungen/wie-definieren-wir-gute-qualitaet/>
33. Zhu S, Li S, Huang J, Fei X, Shen K, Chen X. Time interval between breast cancer diagnosis and surgery is associated with disease outcome. *Sci Rep*. 2023 Jul 26;13(1):12091.
34. De Pietro C, Camenzind P, Sturny I, Crivelli L, Edwards-Garavoglia S, Spranger A, et al. Switzerland: Health system review. 2015. *Health Systems in Transitions*. 17(4):1–288.
35. Bundesamt für Gesundheit. Chancengleichheit in der Gesundheitsversorgung [Internet]. [cited 2024 Oct 23]. Available from: <https://www.bag.admin.ch/bag/de/home/strategie-und-politik/nationale-gesundheitsstrategien/gesundheitsliche-chancengleichheit/chancengleichheit-in-der-gesundheitsversorgung.html>
36. Panczak R, Berlin C, Voorpostel M, Zwahlen M, Egger M. The Swiss neighbourhood index of socioeconomic position: update and re-validation. *Swiss Med Wkly*. 2023 Jan 12;153(1):40028–40028.
37. Leitlinienprogramm Onkologie: German Guideline Program in Oncology (GGPO) [Internet]. [cited 2024 Dec 19]. Available from: <https://www.leitlinienprogramm-onkologie.de/german-guideline-program-in-oncology>
38. ENCR Working Group. ENCR Recommendations Basis of Diagnosis [Internet]. 2022 [cited 2024 Oct 9]. Available from: https://encr.eu/sites/default/files/Recommendations/ENCR%20Recommendation%20BoD_Oct2022_EN_241022.pdf



39. Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF): S3-Leitlinie Früherkennung, Diagnose, Therapie und Nachsorge des Mammakarzinoms, Version 4.4, 2021, AWMF Registernummer: 032-045OL, [Internet]. [cited 2023 Oct 23]. Available from: <https://www.leitlinienprogramm-onkologie.de/leitlinien/mammakarzinom/>
40. Allemani C, Matsuda T, Di Carlo V, Harewood R, Matz M, Nikšić M, et al. Global surveillance of trends in cancer survival 2000–14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries. *The Lancet*. 2018 Mar;391(10125):1023–75.
41. Homepage | ECIS - European Cancer Information System [Internet]. [cited 2024 Oct 9]. Available from: <https://ecis.jrc.ec.europa.eu/en>