Swiss annual Data Quality Report (aDQR)

Most recent year of diagnosis: 2021

December 2024

Introduction

The annual Data Quality Report (aDQR) presents and comments the quality of cancer registry data on the national level. It serves as data quality documentation accompanying the national cancer statistics, as well as for third parties using the NCD.

The National Agency for Cancer Registration (NACR) combines basic and supplementary cancer data from all cantonal cancer registries (CCR's) into a single national cancer dataset (NCD). To ensure a high data quality of the NCD, NACR applies a battery of quality evaluations on a case-by-case basis, and also carries out a systematic comparison of quality indicators (QI's) between CCR's. In order to identify implausible findings, outlier analyses as well as comparisons with internationally acclaimed reference values are made. The results of comparative data quality analyses are compiled in the aDQR, and are discussed with the CCR's so that the registries can track and interpret changes in their own data quality over time.

The aDQR 2021 compares the year of diagnosis 2021, or the years 2020-2021, with previous years (2014 and later). It is based on data from thirteen CCR's in Switzerland, that cover about 90% of the total Swiss population for the period 2014 – 2019. As of 2020, the coverage is 100% (after introduction of the national cancer registration act).

Conclusion

The results show the high overall quality of data held by cancer registries in Switzerland.

The completeness of case ascertainment and the accuracy of the registered information was found to be high, if compared with other European countries.

The completeness of case information showed significant improvements over time and is high for the majority of recorded information as of incidence year 2020. Diagnosis periods with sufficient information for national cancer monitoring were identified.

Comparability of registrations was assessed in the relative homogeneous group of metastasized lung cancer regarding the methods leading to detection of the cancer. While the Swiss average is comparable with results of international studies, a certain heterogeneity was found between registries.

The time interval between diagnosis and registration was found to shorten in consecutive diagnosis years, especially since the inception of the CRA.

A. Quality indicators (QI's): Completeness of case ascertainment

Completeness of case ascertainment (or case finding) evaluates whether all reportable cancer diagnoses made in a defined population have been recorded in the databases of cancer registries.

A1. Number of diagnoses registered and expected ("historical trend")

The observed number of registered diagnoses for 2021 was compared with the expected number of cancer diagnoses 2021. The expectation was based on the modelled historical trend in the underlying rates for 2014 - 2020 and projected to 2021.

Link to table 1: observed and expected diagnoses in 2021

Interpretation:

Registered incidence counts for 2021 remained within the confidence intervals for trend-extrapolated incidence counts for all cancer types analyzed. This result also holds for each CCR (cantonal cancer registry) separately. There is thus no indication of putative under-ascertainment of diagnoses for the year 2021 on the national level.

A2. Ratio of mortality to incidence rate (MIR)

The MIR compares the number of new cancer cases registered in a specific area and time period and the number of deaths due to cancer in the same area and time period. The MIR approximates the case fatality (the proportion of patients who die of a disease). Relying on the fairly complete cause of death statistics in Switzerland [1], the complete ascertainment of diagnoses can be assessed by comparing the MIR values in Switzerland (2017 - 2021) with reference registries, expected to have similar case fatality rates. For this report, the mean MIR of four countries (France, Italy, Austria and Germany) served as references. MIR values in Switzerland higher than expected would indicate potential ascertainment problems.

Link to table 2: mortality to incidence rate (MIR)

Interpretation:

Swiss MIR values were systematically lower than corresponding values for France, Italy, Austria, or Germany. This most likely reflects the slightly better survival rates observed in Switzerland [2]. There is thus no indication of putative under-ascertainment of diagnoses in Switzerland. Only the MIR for urinary bladder cancer was exceptionally high in Switzerland (9.7% higher as the country average). This was because bladder neoplasms with uncertain/in-situ behavior, which are unlikely to cause death, are excluded for incidence rates in Switzerland, in contrast to the comparative countries. Also, the comparison between individual Swiss CCR's did not result in any outlying high values. There is thus no indication of under-ascertainment for the diagnoses 2017 – 2021, as a whole.

A3. Proportion of diagnoses which were registered initially based on a death certificate (DCN)

This indicator measures the proportion of registrations that were triggered by death certificates and were thus missed while the patient was still alive. DCN proportions higher than expected might indicate potential under-ascertainment of diagnoses [3]. Death certificate notified (DCN) percentages for biannual diagnosis years 2020-2021 were compared with 2014-2015, 2016-2017, and 2018-2019.

Link to table 3: DCN

Interpretation:

The proportion of DCN cases decreased over time for most cancer sites. Thus, the analysis of DCN proportions also indicates a decreasing potential for under-ascertainment of cases.

B. Quality indicators (QI's): Accuracy of the registered information

The accuracy (or validity) of the registered cancer data refers to the correspondence between the registered information and the information documented in medical reports. The accuracy depends also on the precision of the source documents and the level of expertise in abstracting, coding, and recording, both in the clinic and the registry.

B1. Death certificate only registrations (DCO)

Cases which are registered only with data available in the death certificate cannot be fully accurate. The QI was determined biannually for diagnosis years 2020-2021, and compared with 2014-2015, 2016-2017, and 2018-2019. Swiss values are compared to other countries.

Link to table 4: DCO

Interpretation:

Proportions of DCO registrations decreased slightly over for most cancer sites, without reaching statistical significance. Swiss DCO values were similar to values in Italy, Spain, and the UK, but much smaller than the values in Germany. There is thus no indication of problems concerning data accuracy on the basis of the DCO analyses.

B2. Diagnoses based on microscopic verification (MV)

The proportion of morphologically or microscopically verified cases indicates the information of the highest validity. The QI was determined biannually for diagnosis years 2020-2021, and compared with 2014-2015, 2016-2017, and 2018-2019. Swiss values are compared to other countries.

Link to table 5: MV

Interpretation:

The proportions of MV are high during 2014-2021, for most cancer sites and have not changed significantly over time. Swiss MV values were similar to values in Germany, Italy, Spain, and the UK in most cancer sites, except for liver, pancreas, lung and brain. For these sites, Swiss MV values were at least 10% higher. This could be related to different diagnostic practices or to under-registration of diagnoses based on clinical methods. The latter explanation is unlikely, because these cancer sites were not flagged in the analysis of the completeness of case ascertainment (see A1 to A3). There is thus indication that the accuracy of diagnosis might be higher in Switzerland as compared with other countries, at least for some cancer sites.

C. Quality indicator (QI): Case completeness

This dimension of data quality concerns unknown and incomplete information on cancer cases. This may be due to the fact that they do not exist, have not been reported to the registry, or were not processed by the registry.

C1. The proportion of cases without specific information

The availability of specific information was assessed for more than 100 variables of the NCD, and for the incidence period 1980 - 2021. Lack of information represents usage of codes for "unknown", "missing", "not stated", or not registering any code (i.e. leaving the variable field empty). Lack of information thus indicates that either this information does not exist at all, or that it was not reported to the cancer registry. Data for diagnosis years < 2020 were collected before the national CRA and the mandatory notification came into force. These data were registered based on canton-specific laws, data collection practices and objectives. Case completeness was assessed for nationally pooled cases, and by individual CCR.

Link to table 6: Case-Completeness_CH

Interpretation:

A data collection is categorized as sufficiently complete for national reporting using the arbitrary completeness level of 75% cases providing specific information as cut off. Only cases where the information in question is highly expected are included, which differs from one variable to the next (see sheet "Case definition" in table 6). We categorize as sufficiently complete, or not complete, the pool of cases over every CCR, and also separately for each CCR. The number of CCRs increased gradually from five in 1980 to thirteen in 2021. A minimum of three CCRs with ≥ 75% case completeness are considered as acceptable for estimating national trends.

Variable groupings	**Variable names** (color coding: see text)	**At least 3 CCRs ≥75%**	**All cases pooled ≥75%**	**% information 2021 (pooled cases)**
Person information	Sex, birthdate, municipality at diagnosis, nationality, vital status follow-up	≥ 1980	≥ 1980	**≈100 %**
	Pseudonymized OASI number	≥ 1987	≥ 1996	**≈100 %**
	Civil status	≥ 1981	≥ 1989	**97 %**
	Cause of death	≥ 1989	≥ 1999	**96 %**
	Birthplace	≥ 1997	≥ 2010	**98 %**
Diagnosis (general information)	Date of notification, date of diagnosis, DCN, basis of diagnosis	≥ 1980	≥ 1980	**≈100 %**
	Method of 1st detection	≥ 1989	≥ 2020	**86 %**
Diagnosis (classifications)	ICD, ICD-O (topography, morphology, behaviour)	≥ 1980	≥ 1980	**≈100 %**
	Laterality	≥ 1984	≥ 1991	**98 %**
	ICD-O grade	≥ 2004	≥ 2020	**75 %**
	Elston/Ellis grade	≥ 1991	≥ 2020	**92 %**
	WHO(CNS) grade	≥ 1993	≥ 2019	**86 %**
	WHO prostate grade	≥ 2017	≥ 2018	**99 %**
	Creasman grade	≥ 2017	≥ 2021	**76 %**
Diagnosis (UICC TNM stage information)	cT, cN, cM	≥ 1994	≥ 2020	71, **77, 94 %**
	pT, pN, pM	(≥ 2016)	≥ 2020	**90,** 70, 5 %
	TNM stage group (registered)	≥ 2003	≥ 2016	**89 %**
	Regional lymph nodes examined/involved	≥ 1999	≥ 2004	**98 %**
	Lymphatic -, venous -, perineural invasion	≥ 2015	≥ 2019	**95, 90, 84 %**
	Pathological tumour size	≥ 2017	-	65 %
	Associated in-situ tumour	≥ 2013	-	19 %
	Topography of metastasis	≥ 2004	≥ 2013	**97 %**
Diagnosis (other stage information)	FIGO	≥ 2003	≥ 2020	**87 %**
	Ann Arbor/Lugano	≥ 2006	-	70 %
	Rai/Binet	≥ 2017	-	57 %
	ISS/DSSplus	-	-	46 %
Breast cancer prognostic factors	ER, PR, HER-2	≥ 2003	≥ 2011	**98 %**
	TPL	≥ 2010	≥ 2016	**96 %**

Prostate cancer prognostic factors	PSA	≥ 1998	≥ 2016	**94 %**
	Gleason score	≥ 2001	≥ 2009	**100 %**
Melanoma prognostic factors	Breslow thickness	≥ 1980	≥ 1987	**97 %**
Colorectal cancer prognostic factors	Microsatellite instability	≥ 2018	-	74 %
	Circumferential resection margin	≥ 2020	-	62 %
Testicular cancer prognostic factors	α-FP, β-hCG, LDH, STM	≥ 2020	≥ 2021	72-76 %
Head and neck cancer prognostic factors	HPV/P16	≥ 2019	≥ 2020	**87 %**
	EBV	-	-	50 %
Treatment-related prognostic factors	Residual in-situ tumour	≥ 2011	-	74 %
	Sentinel lymph node assessment	-	-	54 %
	Resection margins invasive-, in-situ tumour	-	-	55, 54 %
First treatment complex information	Basis of treatment decision	≥ 2019	-	**75 %**
	Treatment component (at least one)	≥ 1984	≥ 2016	**91 %**
	Treatment components (at least two or more)	≥ 2021	-	49 %
Course of disease information	Type of event, date	≥ 2003	≥ 2005	11 %
Supplementary information	Inherited predispositions	-	-	11 %
	Comorbidities (diabetes, liver disease, HIV/AIDS, chronic kidney disease, etc.)	-	-	< 10 %
	Charlson index	-	-	18 %

Table 7. Indication of diagnosis years since when the data are available for national cancer monitoring.
[Abbreviations: ER: estrogen receptor; PR: progesterone receptor; HER-2: HER-2 receptor; TPL: tumour proliferation labeling; PSA: prostate specific antigen; α-FP: α-fetoprotein; β-hCG: humanchorionic gonadotropin; LDH: lactate dehydrogenase; STM: serum tumour markers; HPV/P16: human papillomavirus; EBV: Epstein Barr virus.]

National data for cancer incidence, survival, and prevalence monitoring is based on a sufficiently complete collection since diagnoses of 1980 (variables shaded in green).

Additional stratification of incidence and survival by TNM-, FIGO-, or Ann Arbor/Lugano-stage and ICD-O-, Elston/Ellis-, or WHO(CNS)-grading information, became possible since the mid 2000's, i.e. national estimates can be based on data from at least 3 CCRs (variables shaded in blue). The availability of this information (e.g. TNM-stage) may differ by cancer type. Case completeness for Elston/Ellis, WHO(CNS), and Creasman grade was very heterogeneous between CCRs, before and including 2021. This is partly explained by miss-classification of these grading systems as ICD-O grading.

Prognostic factors for breast or prostate cancer are available since the early 2000's, and Breslow thickness as prognostic factor for melanoma already since 1980 (variables shaded in light red).

Limited information on treatments as part of the first treatment complex is available since 1984 (variable shaded in light grey).

Most other types of information that became mandatory to report with inception of the CRA is only available since diagnoses of 2020, in the majority of cases close to, or surpassing, the cut off value (% numbers in the right column for diagnosis year 2021).

Little information about comorbidity in cancer patients has reached the CCRs, as part of the variables grouped as supplementary information, even for 2021 (variable shaded in dark grey).
Thus, case completeness still can be enhanced by improvements in notification and registration.

D. Quality indicator (QI): Comparability

Comparability is achieved by adherence to national and international guidelines for cancer registration and the standardization of practices amongst the CCR's. This leads to comparable data within each CCR group over time, and between different CCR groups. Due to the large number of variables of the NCD, each annual update of the aDQR highlights a different aspect of data comparability.

D1. Heterogeneity amongst Swiss cancer registries in coding the method leading to the discovery of the cancer

The variable "method of first detection" differentiates between clinical symptoms, incidental discovery, organized screening, opportunistic screening, self-examination, and death with/without autopsy as possible methods leading to the discovery of cancer. There is awareness internationally that scarcity of guidelines regarding this information might lead to heterogeneous coding practices between cancer registries [4].

Link to table 7: Method of 1st detection

Interpretation:

The comparison of coding practice by cancer registry was limited to the relatively homogeneous case mix of lung cancer diagnosed in stage IV (i.e. having distant metastases). Lung cancer was chosen because it furnishes sufficient number of cases, being a major type of cancer, and is not affected by canton-specific organized screening programs, which would create a large amount of expected heterogeneousness in method of 1st detection. Thus, large differences between cancer registries are unlikely explained by true differences, but more likely due to different interpretation of the available information about method of 1st detection.

Three methods of 1st detection dominate: clinical symptoms, incidental discovery, and opportunistic screening. For incidence years 2020-2021 the range of clinical symptoms ranged from 48% to 97% (Swiss average 80%), for incidental discovery from 2% to 49% (Swiss average 16%) and for opportunistic screening from 0% to 7.2% (Swiss average 3.3%). In a recent nationwide registry study in Spain, 27.7% of patients with stage IV lung cancer had no symptoms at diagnosis; in Switzerland the national average for 2020-2021 was 20%. [5]

Although the national average is comparable to the results of an international study, the heterogeneity between the registries is quite high. This is most likely due to the fact that clinical data on the method leading to diagnosis is reported and interpreted differently. However, non-overlapping 99% confidence limits between cancer registry and the Swiss average were found only rarely. The harmonization of the registration of the method leading to the diagnosis will be addressed in 2025 with the cancer registries.

E. Quality indicator (QI): Timeliness

In order to contribute to the development and optimization of the health care system, the published cancer information must be sufficiently recent. Timeliness corresponds to the time interval between diagnosis and the date when the case is included in cancer statistics. This time interval breaks down into different parts: (1) when the information is known until it is reported to the cancer registry, (2) from recording it in the registry database until the finalization of quality checks on the registry level, (3) from submission to the NACR until the finalization of the NCD and the publication date of the first statistical report.
At present, the total interval amounts to about 3 years, which was shown to allow at least 90% completeness of case ascertainment for most types of cancer [6]. The potential for shortening this interval was investigated by analyzing the first step, which is the time from diagnosis to creating the case in the registry database. The QI was determined biannually for diagnosis years 2020-2021, and compared with 2014-2015, 2016-2017, and 2018-2019.

Link to table 8: Timeliness

Interpretation:
The maximal time interval between diagnosis and creating the case in the cancer registry database for the majority of diagnoses existing in the Swiss population amounted to a little over 2 years during 2014-2015, dependent on cancer type (range: 1.9 to 2.3 years). This interval decreased over the following years and dropped sharply to about 1 year for the most recent diagnoses (2020-2021), dependent on cancer type (range: 0.6 to 1.6 years). The observed acceleration is most likely related to the enforcement of the CRA in 1.1.2020, either by faster notification to registries about new diagnoses, or by earlier initiation of the registration process for known diagnoses, or both. It seems possible that cancer statistics, especially incidence rates which require only basic information about cancer and patients, could soon be made available earlier by at least 6 months, as compared with the past. But possible conflicts between data timeliness and other aspects of data quality, foremost completeness of case ascertainment, must be carefully assessed.

Publisher
National Agency for Cancer Registration (www.nacr.ch)

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About us

The National Agency for Cancer Registration (NACR) is a national organization that is responsible for defining the standards for cancer registration, and in which the data on all cancerous diseases that appear in Switzerland are collated. The agency checks the quality of the data and reports it back to the cancer registries. The NACR has shared responsibility with the Federal Statistical Office and the Swiss Childhood Cancer Registry for health reporting at the national level. The NACR transmits to the Federal Statistical Office the data required for national monitoring of cancer. By order of the Federal Department of Home Affairs (FDHA) the Foundation "National Institute for Cancer Epidemiology and Registration (NICER)" is mandated to carry out the tasks of the National Agency for Cancer Registration (NACR).

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