

Swiss annual Data Quality Report (aDQR)

Most recent year of diagnosis: **2020**

EXECUTIVE SUMMARY

September 2024

Introduction

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 annual Data Quality Report (aDQR), and are discussed with the CCR's.

Note: the year of diagnosis 2020 is singular because it represents the first year of data collection under the novel cancer registration act (CRA SR 818.33, 818.331). It is of particular importance to compare the data quality 2020 with previous years.

The aDQR 2020 compared the most recent year of diagnosis submitted to the NACR (2020) with previous years (2017 - 2019). The aDQR was issued in draft form to all CCR's. Each registry was able to compare itself with other registries and track changes in its own data quality over time. Registries with statistically outlying QI's were invited for comment. The aDQR is based on data from thirteen CCR's in Switzerland. These CCR's cover about 90% of the total Swiss population for the period 2017 - 2020.

The present abbreviated and condensed version of the aDQR presents and comments the most important QI's on the national level. This "executive summary" serves as data quality documentation accompanying the national cancer statistics, as well as for third parties using the NCD.

Conclusion

The results show the high overall quality of data held by cancer registries in Switzerland. They also identify areas for action to further improve the quality and homogeneity of registration.

Although 2020 was the year of inception for the Cancer Registration Act (CRA), as well as the national lockdown from 17th of March to 26th of April due to COVID-19, several quality indicators show that the total number of diagnoses remained within expected limits. A single canton did show under-ascertainment of cases caused by temporary problems with the implementation of the CRA, and measures have already been taken by the canton to improve the situation.

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

The evaluation of the completeness of case information showed significant improvements over time. They revealed heterogeneities in registration practices for incidence periods before inception of the CRA, which also improved over time. Incidence periods with sufficient information for national cancer monitoring were identified.

Comparability of data between cancer registries was tested for registration of code "X" in a number of variables addressing disease extent. The coding practices were found to differ between cantonal cancer registries. Harmonization measures are planned for 2025.

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 2020 was compared with the expected number of cancer diagnoses 2020. The expectation was based on the modelled historical trend in the underlying rates for 2013 - 2019 and projected to 2020.

[Link to table 1: observed and expected diagnoses in 2020](#)

Interpretation:

Registered incidence counts for 2020 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, with a single exception (not shown). The under-ascertainment in this canton was caused by temporary problems with the implementation of the CRA, and measures have already been taken by the canton to improve the situation. There is thus no indication of putative under-ascertainment of diagnoses for the year 2020 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 (2016 - 2020) 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 (10.3% higher as the country average). This was because uncertain/in-situ bladder neoplasms, which are unlikely to cause death, are excluded for incidence rates in Switzerland, in contrast to France, Italy, Austria, and Germany. 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 2016 – 2020 combined.

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 alive. DCN proportions higher than expected might indicate potential under-ascertainment of diagnoses. Death certificate notified (DCN) percentages for diagnosis year 2020 were compared with 2017 - 2019.

[Link to table 3: DCN](#)

Interpretation:

The proportion of DCN cases decreased in 2020 for most cancer sites, as compared with the diagnosis period 2017-2019. The CCR-specific analysis identified one CCR with systematically higher DCN proportions for cases diagnosed 2017 – 2019 (not shown), partially due to underusage of so-called hospital lists ("Spitallisten") as sources of information. This had been improved in 2020. Hospital lists as source of information aim to identify cancer cases which are diagnosed based on clinical examination (without microscopical verification).

If the hospital lists are not used to identify these cases, this may lead to more registrations triggered by death certificates. 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 for 2020 and for the period 2017 - 2019, and Switzerland was compared to other countries.

[Link to table 4: DCO](#)

Interpretation:

Proportions of DCO registrations decreased slightly in 2020 for most cancer sites without reaching statistical significance. The CCR-specific analysis identified one CCR with systematically higher DCO proportions for cases diagnosed 2017 - 2019 (not shown), partially due to underusage of so-called hospital lists ("Spitallisten") as sources of information. Hospital lists as source of information aim to identify cancer cases which are diagnosed based on clinical examination (without microscopical verification). If the hospital lists are not used to identify these cases, this may lead to more registrations triggered by death certificates. This issue had been improved in 2020. 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.

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 for 2020 and for the period 2017 - 2019, and Switzerland was compared to other countries.

[Link to table 5: MV](#)

Interpretation:

As for past incidence years, the proportions of MV remained high in 2020 for most cancer sites. Swiss MV values were similar to values in Germany, Italy, Spain, and the UK in most cancer sites, except for liver, pancreas, and brain. For these sites, Swiss MV values were at least 15% 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 is concerned about failure to process reported information, or the registration of code “unknown” for existing but unreported information.

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 - 2020. 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 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 obligation to report came into force. They 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 can be expected are included, which differs from one variable to the next (see sheet “Case definition” in table 6). We categorize 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 2020. A minimum of three CCRs with $\geq 75\%$ case completeness are considered as acceptable for estimating national trends.

Variable groupings	Variable names (color coding see text)	At least 3 CCRs $\geq 75\%$	All cases pooled $\geq 75\%$	% information 2020 (pooled cases)
Person information	Sex, birthdate, municipality at diagnosis, nationality, vital status follow-up	≥ 1980	≥ 1980	$\approx 100\%$
	Pseudonymized OASI number	≥ 1987	≥ 1996	$\approx 100\%$
	Civil status	≥ 1981	≥ 1989	95 %
	Cause of death	≥ 1989	≥ 1999	98 %
	Birthplace	≥ 1997	≥ 2010	78 %
Diagnosis (general information)	Date of notification, date of diagnosis, DCN, basis of diagnosis	≥ 1980	≥ 1980	$\approx 100\%$
	Method of 1 st detection	≥ 1989	≥ 2020	87 %
Diagnosis (classifications)	ICD, ICD-O (topography, morphology, behaviour)	≥ 1980	≥ 1980	$\approx 100\%$
	Laterality	≥ 1984	≥ 1990	98 %
	ICD-O grade	≥ 2004	≥ 2020	76 %
	Elston/Ellis grade	≥ 1995	≥ 2020	78 %
	WHO(CNS) grade	≥ 1995	≥ 2019	74 %
	WHO prostate grade	≥ 2017	≥ 2018	95 %
	Creasman grade	≥ 2017	-	63 %
Diagnosis (UICC TNM stage information)	cT, cN, cM	≥ 1994	-	71, 76, 93 %
	pT, pN, pM	-	-	61, 48, 7 %
	TNM stage group (registered)	≥ 2003	≥ 2016	92 %
	Regional lymph node involvement	≥ 1989	≥ 2000	96 %
	Lymphatic -, venous -, perineural invasion	-	-	54, 55, 54 %
	Clinical -, pathological tumour size	-	-	36, 41 %
	Associated in-situ tumour	-	-	44 %
	Topography of metastasis	≥ 2004	≥ 2013	96 %
Diagnosis (other stage information)	FIGO	≥ 2003	≥ 2020	84 %
	Ann Arbor	≥ 2006	-	70 %
	Binet	≥ 2020	-	55 %
	Lugano	-	-	5 %
	Rai	-	-	29 %
	ISS	-	-	49 %
	DSSplus	-	-	1 %

Breast cancer prognostic factors	ER, PR, HER-2	≥ 2003	≥ 2011	88 %
	TPL	≥ 2010	≥ 2016	96 %
Prostate cancer prognostic factors	PSA	≥ 1998	≥ 2016	94 %
	Gleason score	≥ 2001	≥ 2009	99 %
Melanoma prognostic factors	Breslow thickness	≥ 1980	≥ 1988	98 %
Colorectal cancer prognostic factors	Microsatellite instability	≥ 2018	-	74 %
	Circumferential resection margin	-	-	48 %
Testicular cancer prognostic factors	α-FP, β-hCG, LDH, STM	≥ 2020	-	63-68 %
Head and neck cancer prognostic factors	HPV/P16	≥ 2019	≥ 2020	87 %
	EBV	≥ 2020	-	52 %
Treatment-related prognostic factors	Residual invasive-, in-situ tumour	≥ 2020	-	64, 13 %
	Sentinel lymph node assessment	-	-	54 %
	Number of examined-, positive sentinel nodes	≥ 2019	-	66, 61 %
	Resection margins invasive-, in-situ tumour	-	-	46, 50 %
First treatment complex information	Basis of treatment decision	≥ 2019	-	74 %
	Treatment component (at least one)	≥ 1980	≥ 2016	94 %
	Treatment components (at least two or more)	-	-	47 %
Course of disease information	Type of event, date	≥ 2001	≥ 2005	11 %
Supplementary information	Inherited predispositions	-	-	5 %
	Comorbidities (diabetes, liver disease, HIV/AIDS, chronic kidney disease, etc.)	-	-	< 10 %
	Charlson index	≥ 2014	-	27 %

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: human chorionic 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-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 2020. 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 orange).

Limited information on treatments as part of the first treatment complex is available since 1980 (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 (bold % numbers in the right column).

Little information about comorbidity in cancer patients has reached the CCRs, as part of the variables grouped as supplementary information, even for 2020 (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.

D1. Heterogeneity of using the code category "X" amongst Swiss cancer registries

A number of variables in the NCD concerned with the disease extent contain the official code category "X". There is awareness internationally that coding practices might be heterogeneous [3].

Variable	Definition of code "X"	Number of CCRs not coding "X" *	Range of % "X" in CCRs coding "X"
cT (clinically assessed tumour size)	Primary tumour cannot be assessed.	6	10-41 %
cN (clinically assessed regional lymph nodes involvement)	Regional lymph nodes cannot be assessed.	6	11-33 %
pT (histological assessed tumour size)	Primary tumour cannot be assessed histologically.	10	33-41 %
pN (pathologically assessed regional lymph nodes involvement)	Regional lymph nodes cannot be assessed histologically.	10	50-57 %
Lymphatic invasion	Lymphatic invasion cannot be assessed.	10	6-32 %
Venous invasion	Venous invasion cannot be assessed.	10	5-30 %
Perineural invasion	Perineural invasion cannot be assessed.	11	13-29 %
Residual invasive tumour	Presence of residual tumour cannot be assessed.	10	4-17 %
Residual in-situ tumour	Presence of residual tumour cannot be assessed.	11	2-14 %
Sentinel lymph node assessment	Sentinel lymph node cannot be assessed.	4	9-84 %

*: < 2% of cases are coded as "X"

Table 8. Heterogeneity in usage of code "X"

Interpretation:

There was high variability between Swiss CCRs in the usage of code "X". Some CCRs do not use code "X" at all, while others apply it in > 30% of the eligible cases. The harmonization of coding of this and other types UICC TNM information will be a focus in 2025.

Publisher

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

References

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[Link to the publication](#)
3. On the Use and Abuse of X in the TNM Classification. Greene et al. *CANCER* (2005), p. 647-49, Vol. 103/3.

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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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English

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