

# Swiss annual Data Quality Report (aDQR) 2022 Most recent year of diagnosis: 2019

# **EXECUTIVE SUMMARY**

29.9.2023

## 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 performs different quality evaluations such as a systematic comparison of several quality indicators (QI's) between CCR's. To identify implausible findings, outlier analyses and comparisons with internationally acclaimed reference values are made. The results of these data quality analyses are compiled in the annual Data Quality Report (aDQR).

The aDQR 2022 compared the most recent year of diagnosis submitted to the NACR (2019) with previous years (2014 - 2018). 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 present executive summary of the aDQR 2022 presents and comments the most important QI's 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 aDQR 2022 is based on data from thirteen CCR's in Switzerland. These CCR's cover about 90% of the total Swiss population. Quality indicators were calculated for primary malignant diagnoses only.

# **Summary**

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 registrations.

Several quality analyses showed no indication of under-ascertainment of cases, except a few outlying findings in single cantonal cancer registries. Measures have already been taken by these registries to improve the situation. The accuracy of the registered information was found to be high, especially if compared with other European countries.

The evaluation of the completeness of stage information showed significant improvements over time. They also revealed some heterogeneity in registration practices which need to be addressed.

Comparability of data between cancer registries was tested for DCO (death certificate only) and MV (morphologically verified) cases and was found to be comparable with other European countries.

# A. Quality indicators (QI's) for the completeness of case ascertainment

Completeness of case ascertainment (or case finding) addresses 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 2019 was compared with the expected number of cancer diagnoses 2019 made in the respective population. The expectation was based on the modelled historical trend in the underlying rate for 2012 - 2018 and projected to 2019.

# Link to Table 1: observed and expected cases in 2019

<u>Conclusion:</u> Registered incidence counts for 2019 remained within the confidence intervals for trend-extrapolated incidence counts for all cancer types. The same observation was made for each CCR (cantonal cancer registry) separately (not shown). There was thus no indication of putative under-ascertainment of diagnoses for the year 2019.

# A2. Ratio of mortality to incidence rate (MIR)

The MIR compares the number of new cancer cases registered in a specific area and time and the number of deaths due to cancer in the same area and time. It 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 (2015 - 2019) with reference registries. For this report, the mean MIR of three countries (France, Italy, and Germany) served as references. Higher than expected MIR values in Switzerland would indicate potential ascertainment problems.

## Link to Table 2: MIR

Conclusion: Swiss MIR values were systematically lower than corresponding values for France, Italy, or Germany. This most likely reflects the slightly better survival rates observed in Switzerland [2]. There is no indication of putative under-ascertainment of diagnoses. Only the MIR for urinary bladder cancer was exceptionally high in Switzerland (11.3% higher on average than the references). 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 and Germany. The comparison between CCR's identified an outlying high value in one CCR for multiple myeloma (not shown). Subsequent enquiry by the CCR confirmed the suspicion of under-ascertainment and initiated corrective actions. Another finding was low melanoma rates in one CCR (not shown). This might be explained by the longstanding melanoma awareness campaign in that canton, but further investigations are needed.

## 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. Death certificate notified (DCN) percentages for diagnosis year 2019 were compared with 2014 - 2018.

# Link to Table 3: DCN

<u>Conclusion:</u> The proportion of DCN cases decreased in 2019 for most cancer sites. The CCR-specific analysis identified one CCR with systematically higher DCN proportions for cases diagnosed 2014 - 2018 (not shown), partially due to underusage of so-called hospital lists ("Spitallisten") as sources of information. This had been improved in 2019. Hospital lists as source of information aim to identify cancer cases which are diagnosed based on clinical examination (without microscopical verification).

# B. Quality indicators (QI's) for 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 2019 and for period 2014 - 2018, and Switzerland was compared to other countries.

#### Link to Table 4: DCO

<u>Conclusion:</u> Proportions of DCO registrations decreased slightly in 2019 for most cancer sites without reaching statistical significance. The CCR-specific analysis identified one CCR with systematically higher DCO proportions for cases diagnosed 2014 - 2018 (not shown), partially due to underusage of so-called hospital lists ("Spitallisten") as sources of information. This had been improved in 2019. Swiss DCO values were similar to values in Italy, Spain, and the UK, but much smaller than values in Germany.

# **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 2019 and for period 2014 - 2018, and Switzerland was compared to other countries.

#### Link to Table 5: MV

<u>Conclusion:</u> Proportions MV remained high in 2019 for most cancer sites. Swiss MV values were similar to values in Germany, Italy, Spain, and UK in most cancer sites, except for liver, pancreas, and brain, where Swiss MV values were at least 20% 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).

# C. Quality indicator (QI) for case completeness

This dimension of data quality is concerned about failure to process reported information, or the registration of code "unknown" despite existing information in the reported data.

C1. Unknown UICC (Union for International Cancer Control) Stage-group, and T-, N-, and M- classification The availability of stage information was compared for incidence year(s) 2019 and 2014 - 2018.

## Link to Table 6: unknown Stage

<u>Conclusion:</u> Significantly more cases carried information on stage in 2019 for most cancer sites compared to 2014 - 2018. The CCR-specific analysis documented major differences which could not be explained with differential access to information. During a workshop about aDQR findings, differences in registration practices became apparent. One of the differences in practice concerns missing clinical T-classifications in medical reports. Some CCRs leave this variable empty, others register it based on other information (e.g. the tumour size in mm). These differences in registration practices will be addressed in the future (see Summary).

# D. Quality indicators (QI's) for 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 analysis group over time, and between different analysis groups.

## D1. Degree of heterogeneity in DCO (%) values amongst Swiss cancer registries

The coefficient of variation (CV) is calculated as standard deviation (SD) / Mean. It allows comparison of the degree of heterogeneity between registries of the same country, even if the country specific mean DCO (%) values differ. The CV of DCO (%) in Switzerland was compared with other countries.

#### Link to Table 7: CV for DCO

<u>Conclusion:</u> The coefficients of variation (CV) of DCO (%) for Swiss cantonal cancer registries are slightly higher in comparison with other European countries having a comparable number of regional registries: Germany (9 registries), Italy (36 registries), Spain (13 registries), or the UK (12 registries). On the other hand, the Swiss average DCO (%) values were low in comparison with other European countries. No cancer site could be identified as having unusual high CV amongst Swiss cantonal cancer registries. Heterogeneity may derive from different proportions of traced-back DCN cases, or from different understanding what cases are correctly labeled as DCO. Efforts to reduce heterogeneity in DCO (%) may be taken, but do not seem to be urgent.

# D2. Degree of heterogeneity in MV (%) values amongst Swiss cancer registries

The coefficient of variation (CV) is calculated as SD / Mean. It allows comparison of the degree of heterogeneity between registries of the same country, even if the country specific mean MV (%) values differ. The CV of MV (%) in Switzerland was compared with other countries.

#### Link to Table 8: CV for MV

<u>Conclusion:</u> The coefficients of variation (CV) of MV (%) for Swiss cantonal cancer registries are small in comparison with other European countries having a comparable number of regional registries: Germany (9 registries), Italy (36 registries), Spain (13 registries), or UK (12 registries). The Swiss average MV (%) values were high in comparison with other European countries. Liver cancer could be identified as having unusual high CV amongst Swiss cantonal cancer registries, which is however comparable with findings in other countries. Efforts to reduce heterogeneity in MV (%) are not required.

#### References:

- 1. Cause of death and stillbirth statistics (eCOD) in Switzerland. Link to the Federal Statistical Office
- 2. Cancer in Switzerland 2021. www.krebs.bfs.admin.ch ISBN: 978-3-303-14333-9. Link to the publication

## **Acknowledgements**

The National Agency for Cancer Registration wishes to acknowledge the work of all the staff working in the Swiss Cantonal Cancer Registries, who provided the raw data for these analyses.

#### 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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