Indicators of data quality at the Cancer Registry Zurich and Zug in Switzerland

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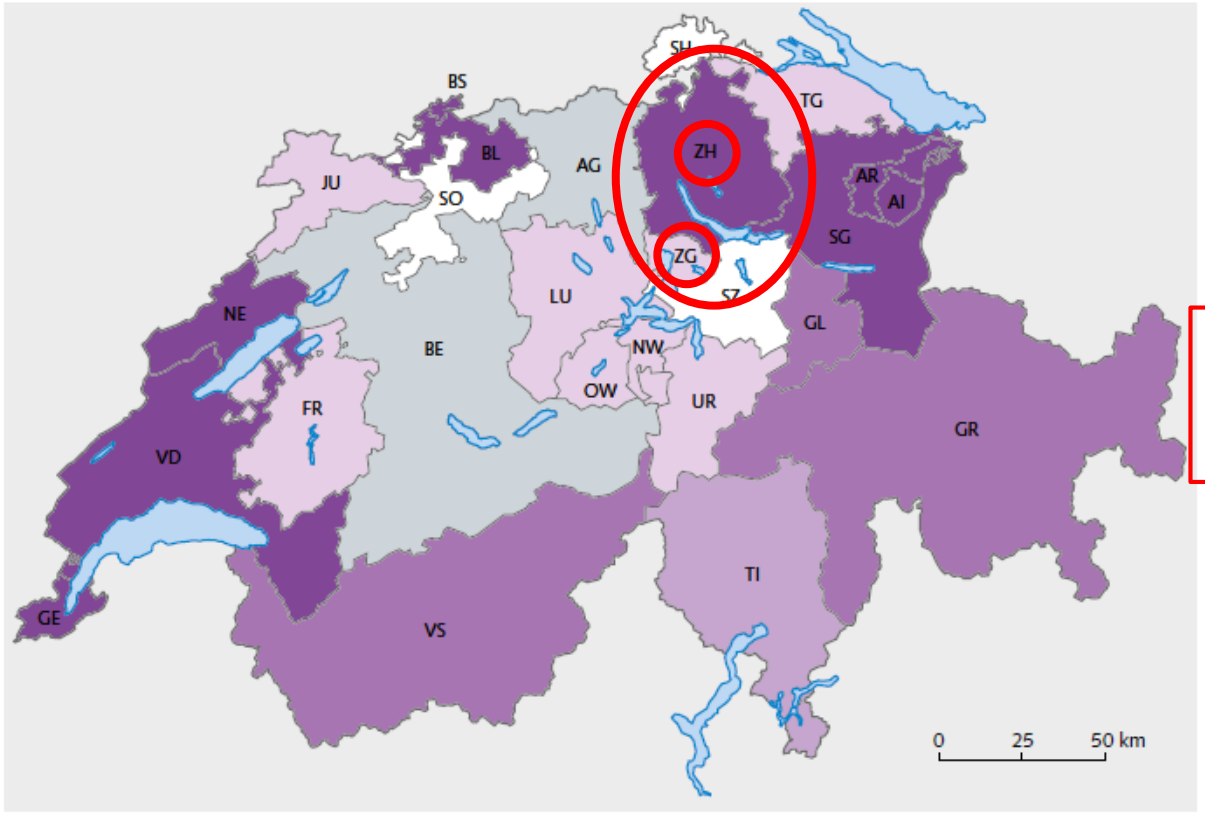
Background - Cancer registration in CH

15 regional/cantonal cancer registries, with the National Institute for Cancer Epidemiology and Registration (NICER) consolidating the national data

Cantons with cancer registration, 2015 M 1



ZH+ZG:
Area: 5% of total CH
Population: 20% of total CH

Spatial division: Cantons

Source: NICER, CCR

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Background – Cancer registration in CH

- Population: 8.37 Mio inhabitants (2016)
- Most cantons have a cancer registry
- Three cantons without cancer registry
- New national law on cancer registration will come into force:
  - January 2020
  - Cancer registration will be mandatory for all cantons

Background – Cancer Registry ZH und ZG

Zurich (ZH)

- Population: 1.49 Mio (2016)
- Cancer registration since **1980**
- Cantonal law came into force in January **2017**

Zug (ZG)

- Population: 0.12 Mio (2016)
- Cancer registration since **2011**, based on an ordinance

Organising institutions:

- Institute of Pathology and Molecular Pathology (University Hospital Zurich)
- Epidemiology, Biostatistics and Prevention Institute (University of Zurich)

Background – Indicators of data quality

Four common indicators of data quality:

- **Comparability**
  - Adherence to agreed international guidelines
- **Validity (accuracy)**
  - Proportion of cases with a given characteristic that truly have the attribute
- **Timeliness**
  - Rapidity of collecting, processing and reporting cancer data
- **Completeness**
  - Extent to which all incident cancer cases occurring in the population are included in the cancer registry database

Bray & Parkin 2009
Parkin & Bray 2009

Methods – Data Sources and Data

- The Cancer Registry ZH/ZG receives data from:
  - Pathology and haematology laboratories
  - Hospitals
  - Physicians
  - Federal Statistical Office (death certificates)
  - Citizen service departments (vital status follow-up)
- Included data:
  - Malignant cancer cases (C00-C99, excluding C44)
- Vital status follow-up not complete → no methods including survival were applied

Methods – Indicators and time periods

- Presented indicators:
  - **Comparability:** general description of adherence to international guidelines
  - **Validity:** DCO, DCN, MV%, CUP (=C80)
  - **Timeliness:** comparison of incident cases published in annual reports
  - **Completeness:** stability of incidence rates over time, M:I ratios, age-specific incidence rates for childhood cancer
- Time periods:
  - 1980/1-2014: incidence data, CUP, M:I
  - 1997-2014: DCO, MV%
  - 2009-2014: DCN

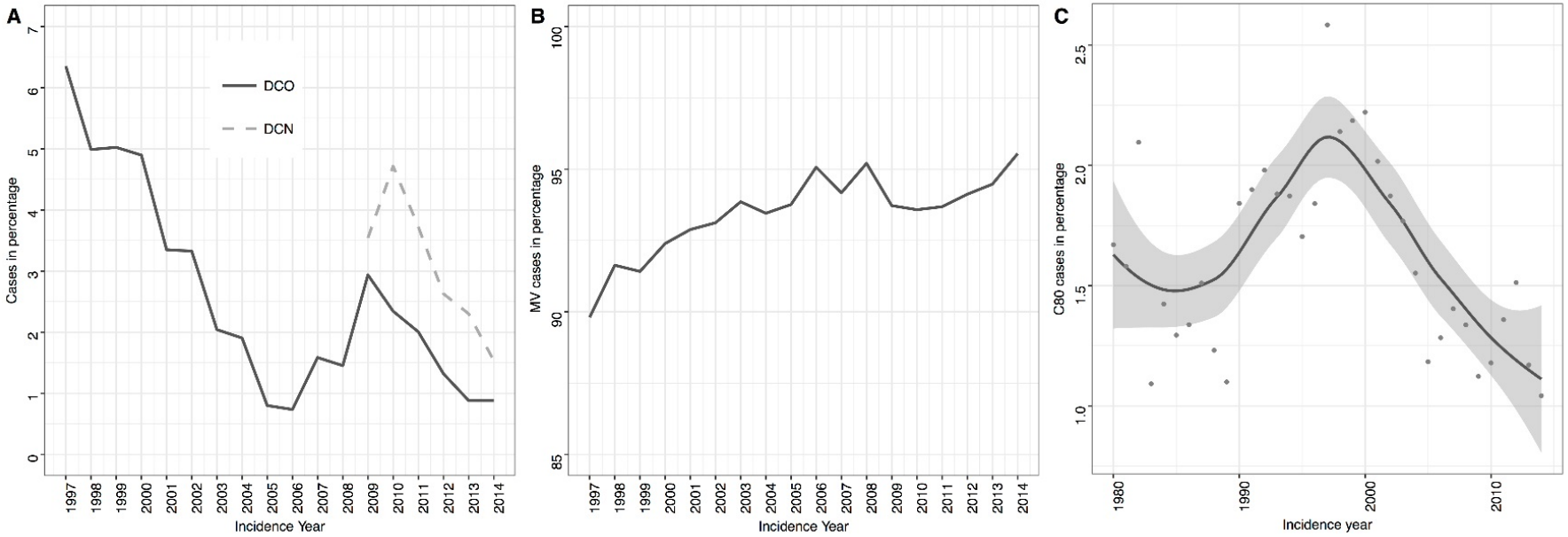
Results - Comparability

All cancer cases recorded according to international standards:

- ICD / ICD-O:
  - 1980-2002: ICD-9, ICD-O-1
  - since 2003: ICD-10, ICD-O-3
- TNM (UICC):
  - 1980-1994: TNM 3
  - 1995-1997: TNM 4
  - 1998-2002: TNM 5
  - 2003-2009: TNM 6
  - since 2010: TNM 7
- Incidence dates according to ENCR
- Basis of diagnosis according to IARC/IACR
- Multiple primaries according to ENCR

Jensen, 1991
Tyczynski, Démaret and Parkin, 2003

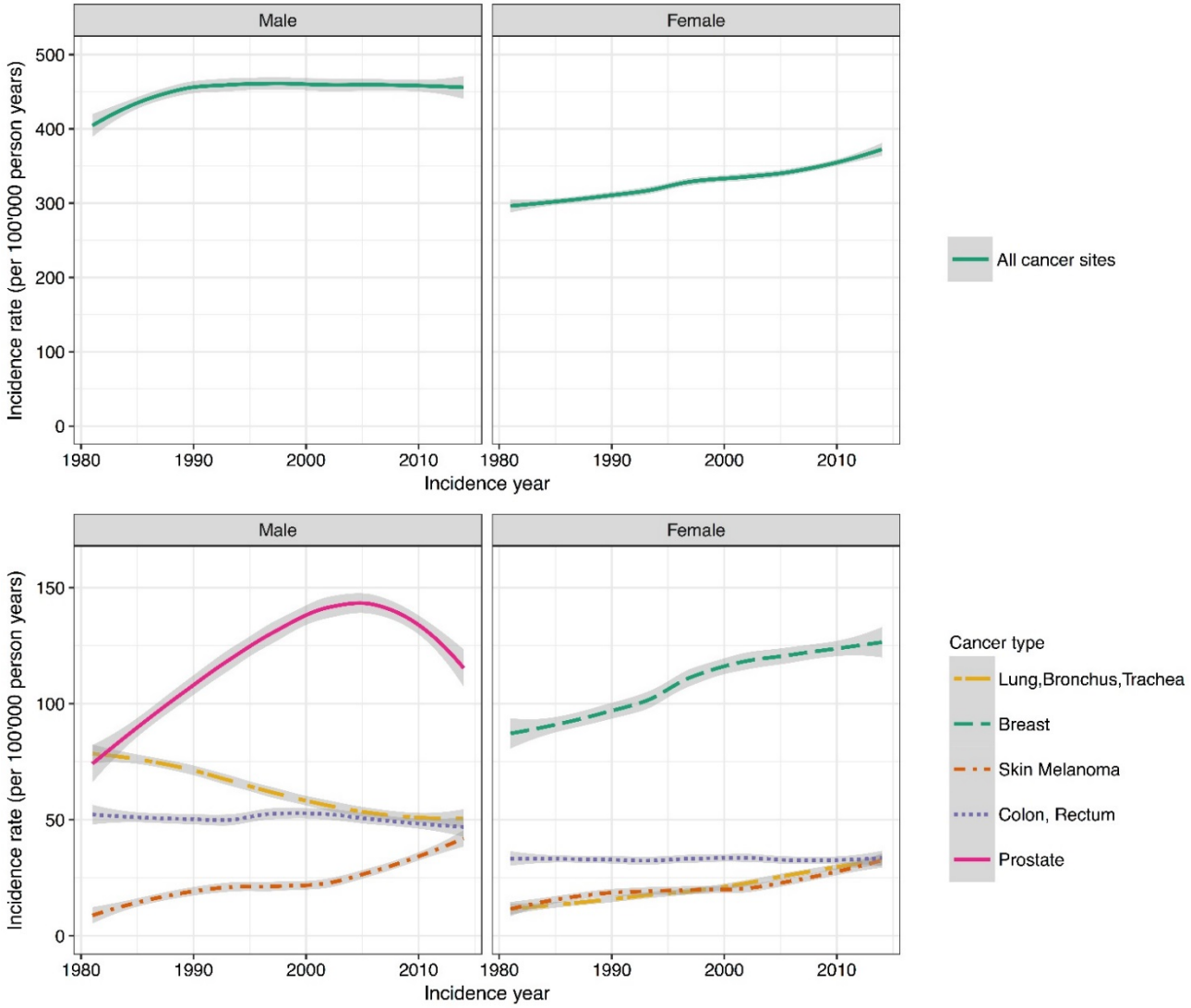
Results - Validity



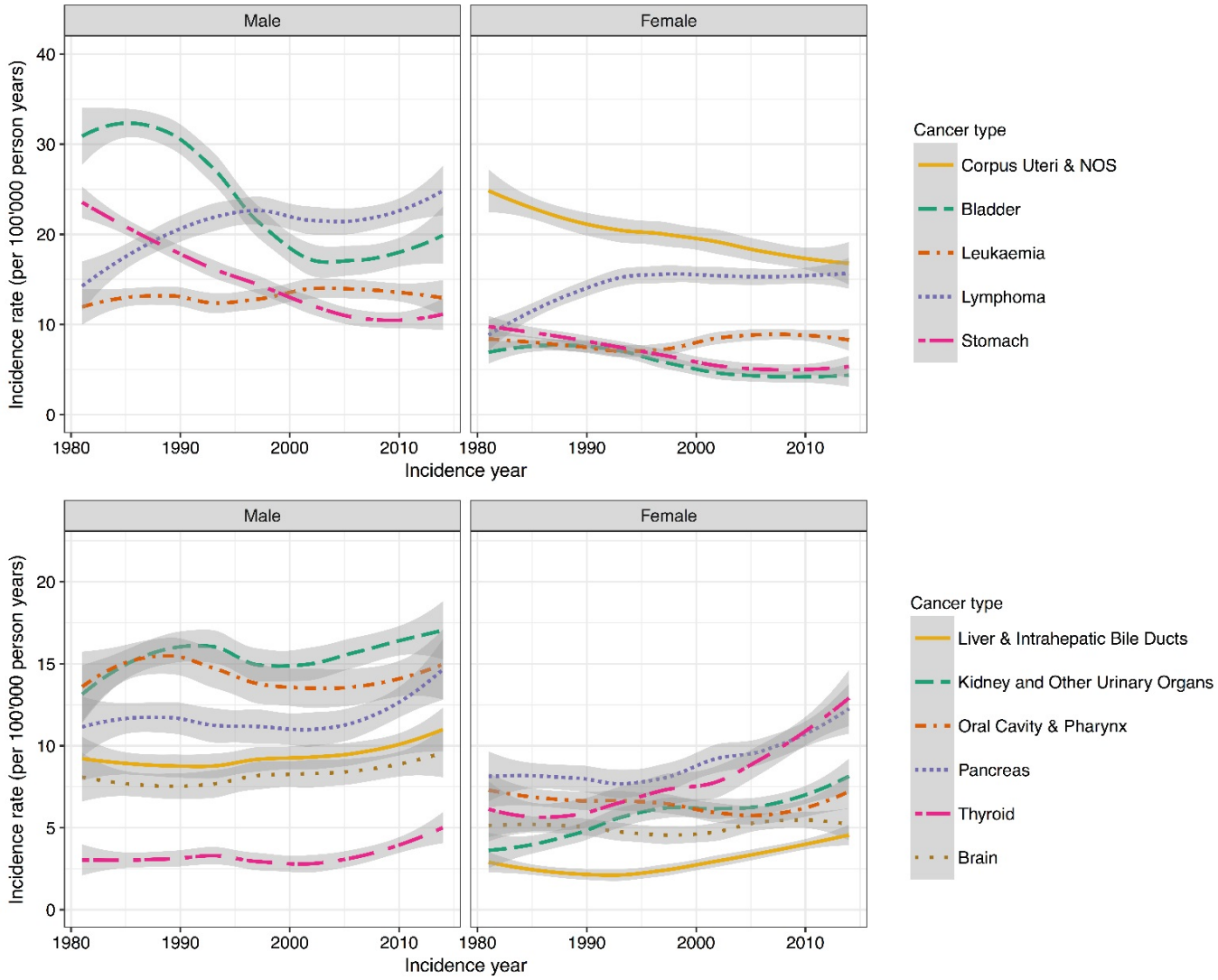
Results - Timeliness

- At CR ZH/ZG, incident cases are completed with two-year delay
- About 2.5% of cases registered 1 year later than intended
- For most localisations, difference of cases published within two years after diagnosis and within three years of diagnosis was <5% but was somewhat higher for leukaemia and liver cancer (up to 10 percent)

Results – Completeness I: ASR



Results – Completeness II: ASR



Results – Completeness III: childhood ASR

Age	Boys			Girls		
	Ref: lowest decile	CR ZH 1981-2015	Ref: highest decile	Ref: lowest decile	CR ZH 1981-2015	Ref: highest decile
0-4	<12.3	24.3	>24.7	<9.7	17.0	>21.4
5-9	<8.5	13.1	>15.6	<6.9	10.0	>12.0
10-14	<8.5	13.0	>15.0	<6.8	10.5	>13.6

Reference values: Lowest and highest deciles for childhood cancer incidence rates in CI5 Vol. VIII (Parkin et al., 2002)

Results – Completeness IV: M:I ratios

- M:I ratios decreased from 0.58 (1980) to 0.37 (2014)
- Cancer with poor survival rates had M:I close to 1
- Cancer with good survival rates had M:I rates close to 0

Conclusions I

- Comparability:
  - Generally following the international standards and rules
- Validity:
  - DCO rate decreased from >6% (1997) to <1% (2014), <5% since 2001
  - Increase in MV% from 89.7% (1997) to 95.5% (2014)
  - CUP overall low (<3%)

Conclusions II

- Timeliness (→ standard: <24 months (Bray & Parkin, 2009))
  - 95% of cases registered within two years
  - For leukaemia, proportion lower (~90%) → often diagnosed in outpatient settings
- Completeness:
  - Generally increasing trend, similar to other Western countries
  - Childhood incidence rates within reference values
  - Site-specific M:I ratios comparable to other European countries

Conclusions III

- Access to data is relatively good, will improve with new law
- Most indicators improved over time
- In general, the data quality is good
- Draw-back is limited access to vital status data up to 2018

Publication (→ open access)

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Research Article

Indicators of Data Quality at the Cancer Registry Zurich and Zug in Switzerland

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Data quality is an important issue in cancer registration. This paper provides a comprehensive overview of the four main data quality indicators (comparability, validity, timeliness, and completeness) for the Cancer Registry Zurich and Zug (Switzerland). We extracted all malignant cancer cases (excluding non-melanoma skin cancer) diagnosed between 1980 and 2014 in the canton of Zurich. Methods included the proportion of morphologically verified cases (MV%), the proportion of DCN and DCO cases (2009–2014), cases with primary site uncertain (PSU%), the stability of incidence rates over time, age-specific incidence rates for childhood cancer, and mortality:incidence (MI) ratios. The DCO rate decreased from 6.4% in 1997 to 0.8% in 2014 and was <5% since 2000. MV% was 95.5% in 2014. PSU% was <3% over the whole period. The incidence rate of all tumours increased over time with site-specific fluctuations. The overall M:I ratio decreased from 0.58 in 1980 to 0.37 in 2014. Overall, data quality of the Cancer Registry Zurich and Zug was acceptable according to the methods presented in this review. Most indicators improved over time with low DCO rates, high MV%, low PSU%, relatively low M:I ratios and age-specific incidence of childhood cancer within reference ranges.