

EVALUATION of COMPLETENESS OF CASE ASCERTAINMENT in SWISS CANCER REGISTRATION

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Objective and Background

- The value of population-based cancer registries (CRs) depends strongly on completeness of case ascertainment, i.e. the extent to which all diagnosed neoplasms are included in the registry database. This is the first comprehensive evaluation of completeness in Swiss cancer registration.
- No gold-standard approach is available to assess completeness. We applied simple as well as dedicated methods and focus on replicated outcomes.

Data and Methods

This study is based on the National Core Dataset (NCD) managed by the National Institute for Cancer Epidemiology and Registration (NICER) with the purpose of national cancer monitoring in Switzerland. Mortality statistics were derived from the Swiss Federal Statistical Office. All 10 Swiss cancer registries (CR) in operation since at least 2006 are included in this report: St. Gall-Appenzell, Basel, Fribourg, Geneva, Grison and Glarus, Neuchatel and Jura, Ticino, Valais, Vaud, and Zurich. CRs recorded all incident cancer cases diagnosed in their permanent resident population and followed-up cases' survival until at least 2012. Primary malignant neoplasms 2006 to 2011 were pooled, except for Basel where cases from 2006 to 2009 were available at the time of analysis.

Simple measures from routine statistics: %DCN, %DCO, %MV

Cancer type	Swiss Cancer registry																																
	Zurich			Fribourg			Ticino			Valais			Geneva			Basel			St. Gall /App.			Grison /Glarus			Neuch. /Jura			Vaud			All CRs		
	DCN	DCO	MV	DCN	DCO	MV	DCN	DCO	MV	DCN	DCO	MV	DCN	DCO	MV	DCN	DCO	MV	DCN	DCO	MV	DCN	DCO	MV	DCN	DCO	MV	DCN	DCO	MV	DCN	DCO	MV
Lip, oral cavity and pharynx																																	
Oesophagus																																	
Stomach																																	
Colon, rectum and anus																																	
Liver																																	
Pancreas																																	
Lung (incl. trachea)																																	
Melanoma of the skin																																	
Breast (female)																																	
Cervix and corpus uteri																																	
Ovary																																	
Prostate																																	
Kidney																																	
Bladder																																	
Eye, brain and CNS																																	
Hodgkin lymphoma																																	
Non-Hodgkin lymphoma																																	
Multiple myeloma																																	
Lymphoid leukaemia																																	
Myeloid leukaemia																																	
All sites																																	

Tab. 1. Simple measures of validity, such as %DCN, %DCO, and %MV, are also used as indirect indicators for completeness. %DCN or %DCO $\geq 10\%$ are flagged in yellow. Cases of unexpected high %MV are flagged in red. Grey colour indicates missing information.

Comparably high proportions of cancer registrations initiated by a death certificate (%DCN) indicate possible under-registration because death certificates not always mention an existing cancer diagnosis (Ref. 1). Proportions of death certificate only (%DCO) registrations provide a lower limit of %DCN, if %DCN is missing.

In the majority of CRs, %DCN (or %DCO) were $\geq 10\%$ only for pancreatic or hepatic cancer (Tab. 1). Because this is not unusual in international comparison (Ref. 2), such cases are **flagged in yellow**, indicating weak but existing potential of under-registration.

If comparably high proportions of diagnoses are verified microscopically by cytology/haematology or histology (%MV), it might indicate over-reliance on the pathology laboratory as source of information and failure to find cases diagnosed by other means (Ref. 1). We **flagged in red** individual %MV for being significantly greater than the pooled value of all ten Swiss CRs.

Only hepatic cancer in Basel was flagged as being potentially under-registered.

MI/Surv-Method (semi-quantitative): Mortality/Incidence (MI) Ratio vs 1-Relative Survival

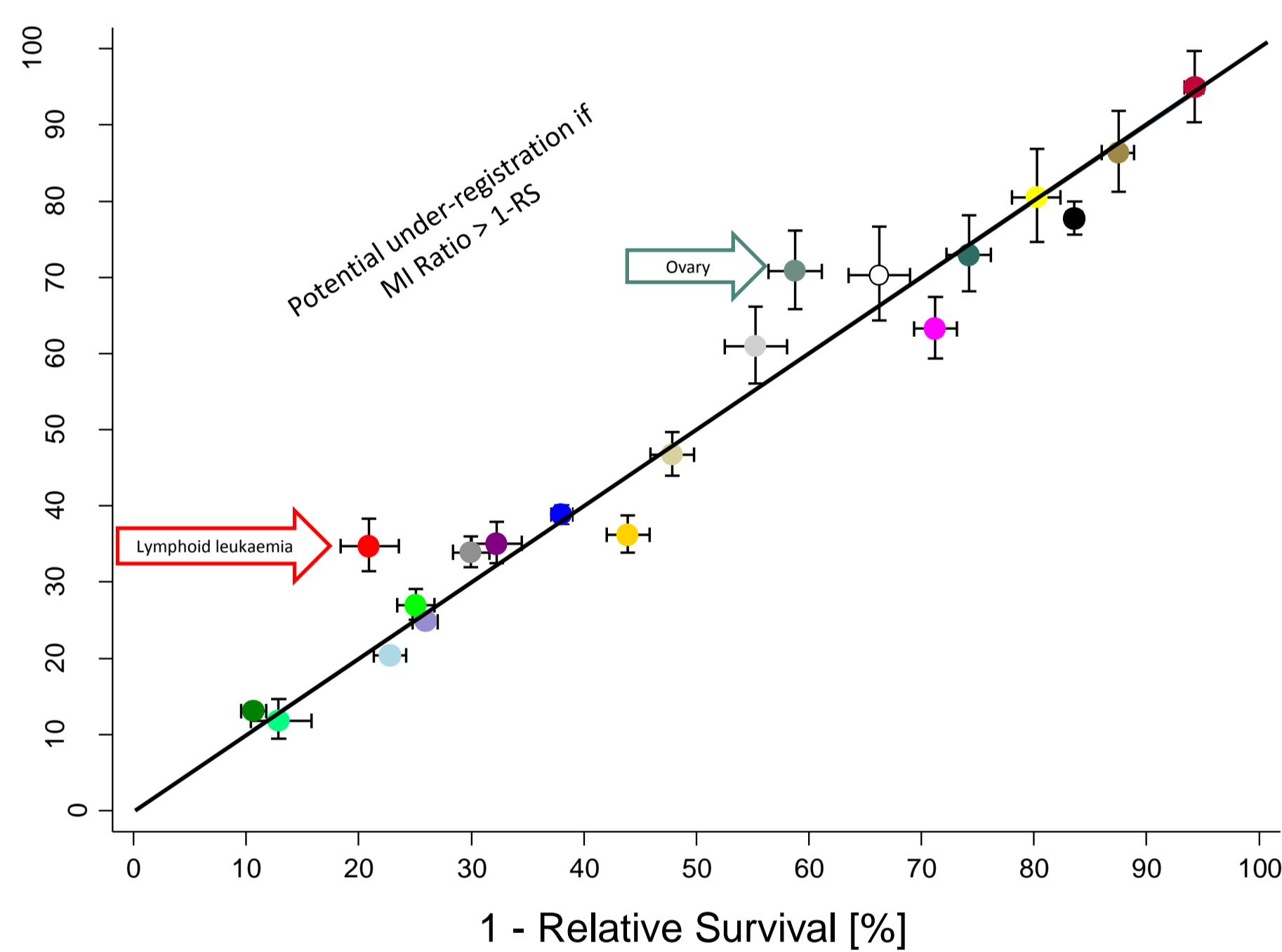


Fig. 1. Mortality/Incidence (MI) Ratios and 1-Relative Survival for pooled CR data.

Cancer type	Swiss Cancer registry										
	Zurich	Fribourg	Ticino	Valais	Geneva	Basel	St. Gall /App.	Grison /Glarus	Neuch. /Jura	Vaud	All CRs
Lip, oral cavity and pharynx											
Oesophagus											
Stomach											
Colon, rectum and anus											
Liver											
Pancreas											
Lung (incl. trachea)											
Melanoma of the skin											
Breast (female)											
Cervix and corpus uteri											
Ovary											
Prostate											
Kidney											
Bladder											
Eye, brain and CNS											
Hodgkin lymphoma											
Non-Hodgkin lymphoma											
Multiple myeloma											
Lymphoid leukaemia											
Myeloid leukaemia											
All sites											

Tab. 2. Colour-coded difference between MI Ratio and 1-Relative Survival. Flagged cases in red. Grey cases were not determined due to lack of vital-status information at the time of analysis.

The MI Ratio is expected to be similar to the complement of crude 5-year relative survival (Ref. 3). Unexpected large MI Ratios, e.g. those above the diagonal in Fig. 1, indicate potential under-registration. We **flagged in red** all cases as potentially under-registered if the MI Ratio was $\geq 10\%$ larger and significantly different from 1-Relative survival (Tab. 2).

Only lymphoid leukaemia was systematically flagged in a majority of CRs, and in pooled data.

CR-specific flags were found for ovarian, hepatic, and pancreatic cancer in Basel.

Flow-Method (quantitative): direct estimation of completeness

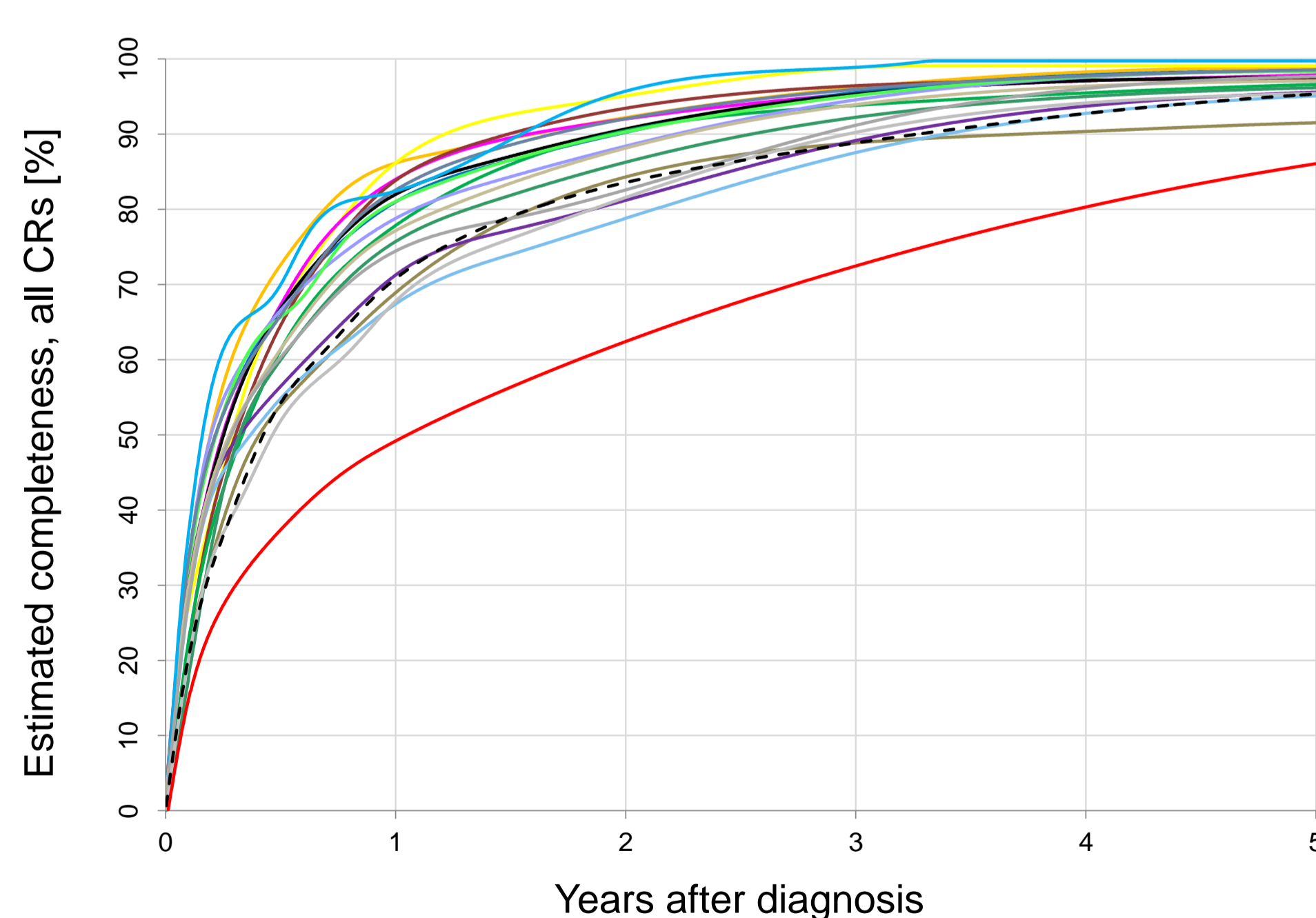


Fig. 2. Flow-method estimated completeness curves for pooled CR data.

Cancer type	Swiss Cancer registry										
	Zurich	Fribourg	Ticino	Valais	Geneva	Basel	St. Gall /App.	Grison /Glarus	Neuch. /Jura	Vaud	All CRs
Lip, oral cavity and pharynx											
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Lymphoid leukaemia											
Myeloid leukaemia											
All sites											

Tab. 3. Colour-coded Flow-method estimates for completeness at 3 years after diagnosis. Flagged cases in red. Grey cases were not determined due to lack of required parameters at the time of analysis.

The Flow-method models the dynamics of the cancer registration process (Fig. 2; Ref. 4).

The international level for satisfactory completeness of 90% was reached approximately 3 years after the diagnosis, for some cancer types already at 2 years (Fig. 2).

Completeness was **flagged in red** if the value at 3 years after diagnosis was $< 80\%$, or if upper limit of the confidence interval excluded 90% (Tab. 3).

Only lymphoid leukaemia seemed to be systematically under-registered. There were CR-specific findings in ZH (prostate cancer, kidney cancer, non-Hodgkin lymphoma), and in VS (prostate cancer).

Conclusion and Perspectives

- Registration via death certificate is frequent for hepatic and pancreatic cancer in the majority of Swiss CRs. This alone is not indicative of under-registration as shown by the general lack of flagging by other methods.
- The MI/Surv- and Flow-Methods are dedicated to assess completeness. The only cancer repeatedly flagged for potential under-registration by these methods was lymphoid leukaemia. Disagreement about potential under-registration of other cancers must be carefully qualified with respect to method-specific assumptions. Under-registration of hepatic and pancreatic cancer in Basel is very likely due to exceptionally large MI ratios (not shown).
- As next steps, we will follow up flagged cancer types in individual CRs to verify the findings and identify ways of improvement. Future studies will assess completeness depending of factors such as age at diagnosis and temporal completeness trends.