

Follow-up registration and completeness in Switzerland

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BACKGROUND & METHODS

BACKGROUND

Cancer registration in Switzerland is organised at the cantonal level with varying legal bases and financial resources. As this is likely to affect data quality and completeness a survey was conducted, focusing on the process of active follow up. Up to now prevalence and survival is not part of Swiss national cancer monitoring on a regular base. Therefore, main quality and completeness checks at the national level focus on incidence information only.

DATA SOURCES

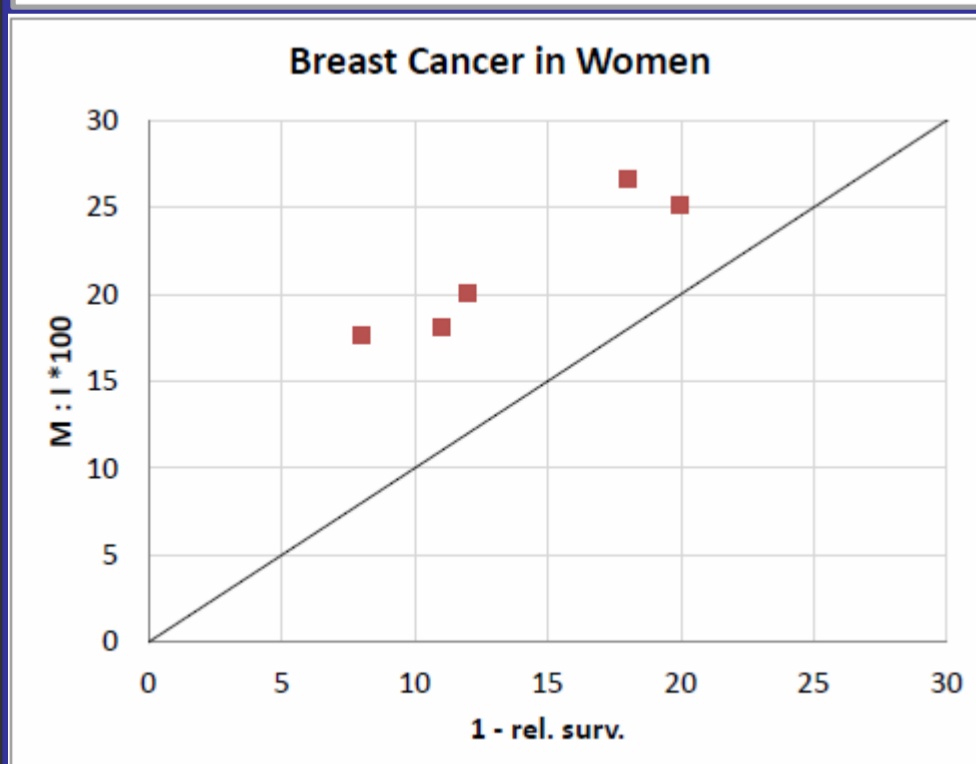
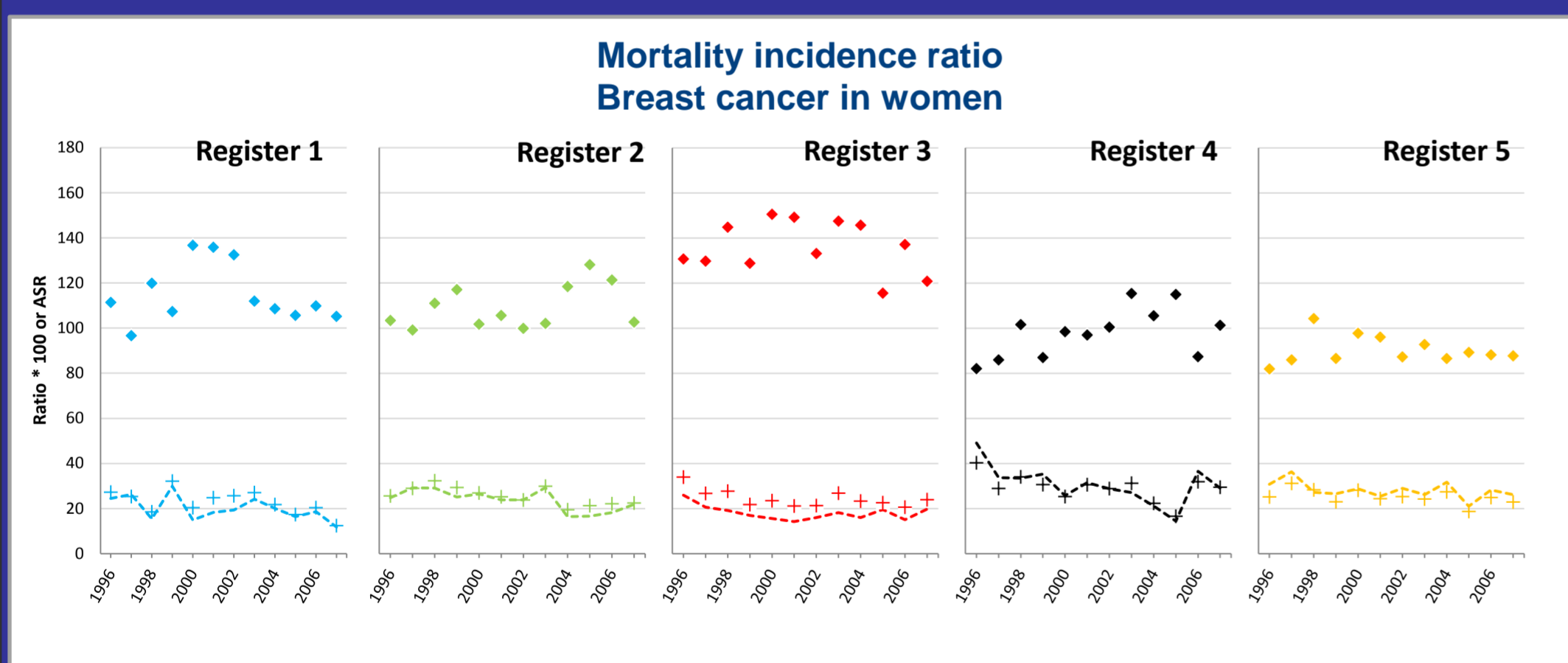
Data for this exercise came from the annual NICER data quality reports, NICER completeness analysis, the cancer registry questionnaire of Concord 2 and CI5 and a NICER questionnaire about the process of active follow-up.

COMPLETENESS OF CASE ASCERTAINMENT

RESULTS

The significance of data from population based cancer registries depends strongly on the completeness of case ascertainment. One indirect indicator, commonly used, is the mortality incidence ratio. To calculate the M:I ratio, the incidence from a cancer registry and reported mortality statistics in the same period are used. Whereas differences between tumour entities as well as long-term decrease of M:I ratio in time series are probably explainable with different or increasing survival time, a sudden increase of M:I ratio implies decreasing completeness of case ascertainment. Since the M:I ratio is approximately equal to 1-5 year relative survival the expected M:I ratio can be estimated from a pooled analysis. The ratio between M:I ratio and 1-5 year survival should be approximately 1 for all cancer sites.

For five Swiss cancer registries mortality incidence ratios were used to assess completeness in a comparative way. The involved registries cover 24 % of the Swiss population and 37 % of the population under registration. Results are presented for breast cancer in women.



Results show systematic higher M:Is for breast cancer which can be an indicator for underreporting. Alternatively, the results can be caused by an overestimation of the cured proportion by 1 minus 5-year survival as long term survival is known to stay reduced in breast cancer cases.

COMPLETENESS OF FOLLOW-UP

RESULTS

The survey uncovered variations in the frequency of active follow up on cantonal level ranging from a weekly investigation up to 5 year period. One canton is doing active follow up only within the framework of specific studies.

In most cantons, follow up information is compiled for all malignant cancers and carcinoma in situ whereas in other cantons only specific malignant cancers are considered. In more than half of the cantons written requests have to be sent to cantonal and/or community inhabitant control offices to investigate vital status, the remaining one have electronic connections. Most registries define lost-to-follow-up by cantonal boundaries, at least two registries by national boundaries.

Documentation of follow up status for the national level is mandatory in 11 cantons for breast cancer and colorectal cancer only (at least once every 5th or 6th year for each case). 2 fail to achieve this rate. The variation in completeness is illustrated by presenting figures for three selected registries.

year of incidence	Proportion of cases without follow-up information					
	breast cancer			colorectal cancer		
	Reg 1* %	Reg 2* %	Reg 3* %	Reg 1* %	Reg 2* %	Reg 3* %
2009	38.0	0.0	0.0	23.7	2.1	0.0
2008	50.1	1.2	0.0	31.9	0.0	0.0
2007	54.4	0.7	0.0	9.4	0.0	0.0
2006	37.2	6.8	0.0	0.9	5.0	0.0
2005	0.4	3.8	0.0	0.5	12.3	0.0
≤ 2004	19.4	0.4	0.0	8.5	0.6	0.0

* selected cancer registries

year of last follow-up	Proportion of cases without recent follow-up					
	breast cancer			colorectal cancer		
	Reg 1* %	Reg 2* %	Reg 3* %	Reg 1* %	Reg 2* %	Reg 3* %
≤ 2009	22.7	17.1	0.0	11.5	9.1	0.0
≤ 2008	20.3	13.4	0.0	10.4	7.5	0.0
≤ 2007	16.8	11.5	0.0	9.9	6.4	0.0
≤ 2006	14.4	9.3	0.0	9.7	4.9	0.0
≤ 2005	14.0	9.7	0.0	9.9	5.1	0.0
≤ 2004	12.6	3.6	0.0	7.5	0.4	0.0

* selected cancer registries

SELECTED REFERENCES

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CONCLUSION

Federal structures without national framework legislation can lead to a high variation concerning procedures, data quality and completeness of follow up registration.