EVALUATING COMPLETENESS OF CANCER REGISTRATION IN SWITZERLAND

Fabio Montanaro[1], Silvia Ess[2], Daniel De Weck[3], Andrea Bordoni[1], Pierre Pury[4], Jean-Michel Lutz[4,5]

[1]Registro Tumori Canton Ticino, Locarno, fabio.montanaro@ti.ch

[2]Krebsregister St.Gallen-Appenzell, St. Gallen

[3]Registre valaisan des tumeurs, Sion

[4] Association of Swiss Cancer Registries, Geneve

[5]Registre genevois des tumeurs, Geneve

Common methods to estimate completeness of cancer registration

- Incidence / mortality ratio
- Capture-recapture
- Re-ascertainment

- Each of these methods suffers from some limitation:

Based upon strong assumptions

and/or

Too expensive and time consuming

and/or

Completeness Estimated at a single point in time

Method used in the present study: "FLOW" method

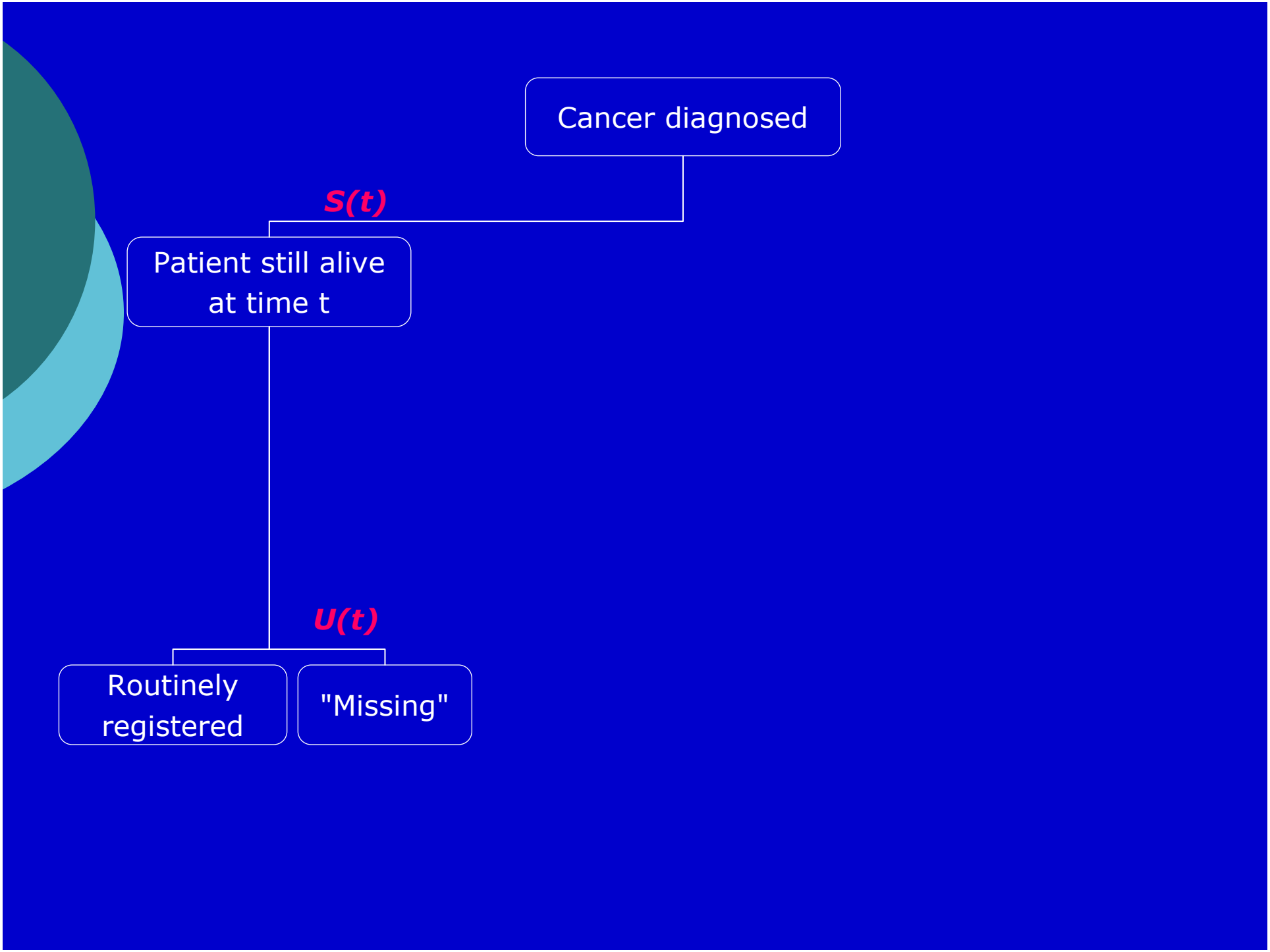
(Firstly used at Thames Cancer Registry (UK) in 1995*)

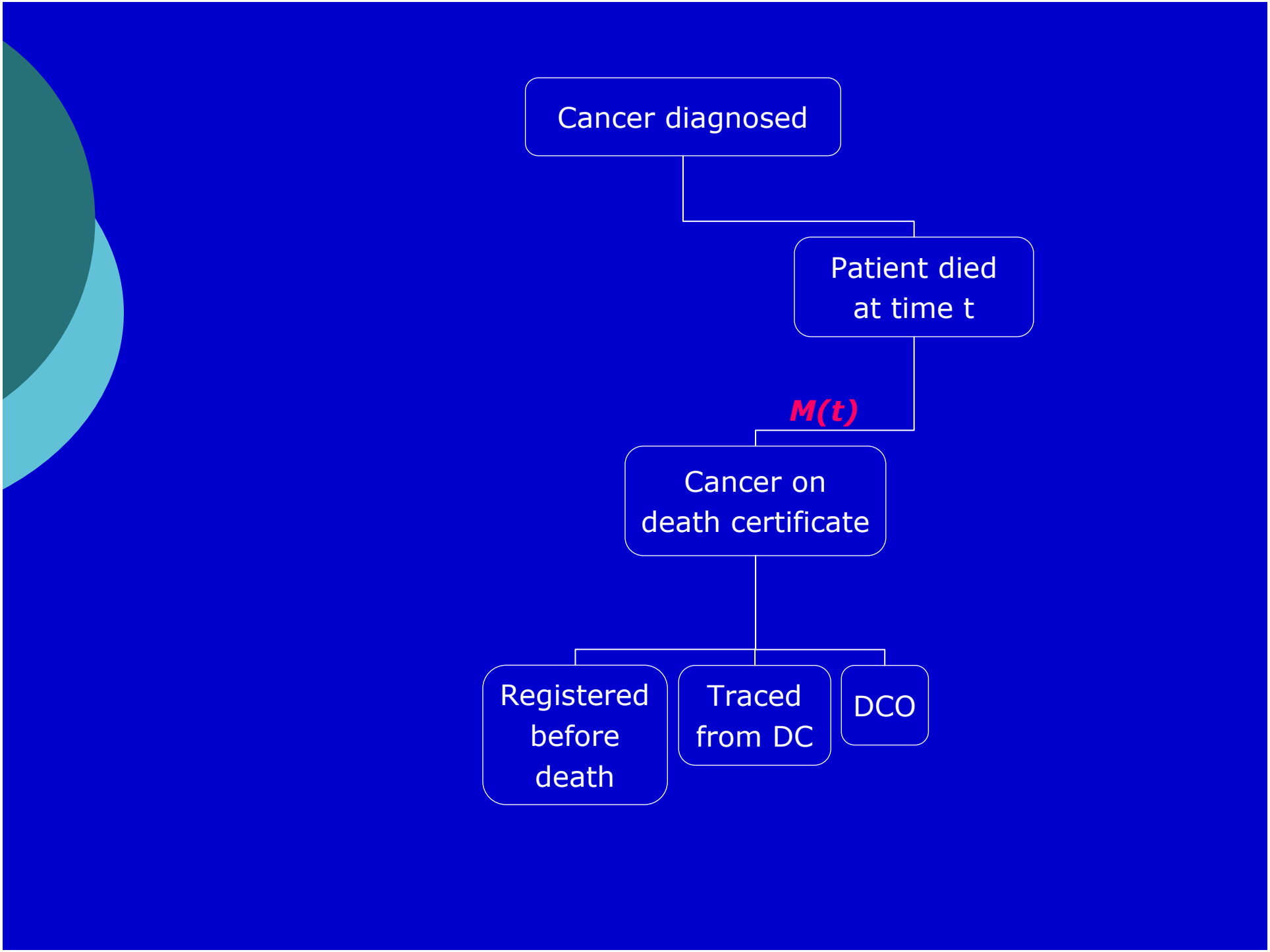
- **Characteristics and advantages:**
  - **It is simple and cheap to be applied (if required information are routinely registered)**
  - **It shows how completeness increases with time since diagnosis at different time points**
  - **It can be applied either globally or for specific tumour sites, with graphics**
  - **Its interpretation does not depend on assumption made on other cancer registries or other data sources**
  - **It estimates the percentage of cancer patients who are likely to be never registered (the "lost" group)**

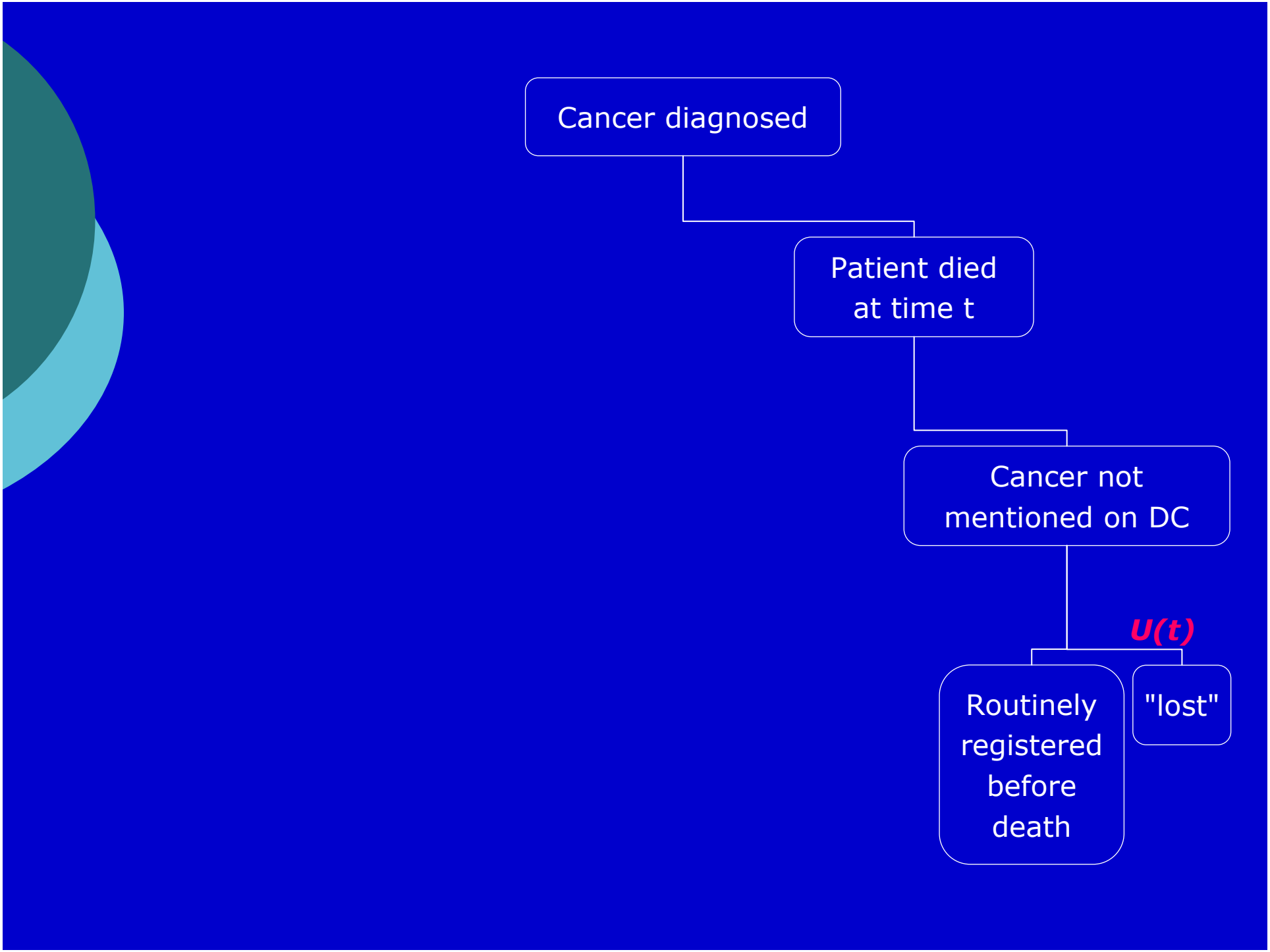
*J. Bullard, MP. Coleman, D. Robinson, J-M. Lutz, J. Bell, J. Peto. *Completeness of cancer registration : a new method for routine use*, British J of Cancer, 82 (5), 1111-16, 2000

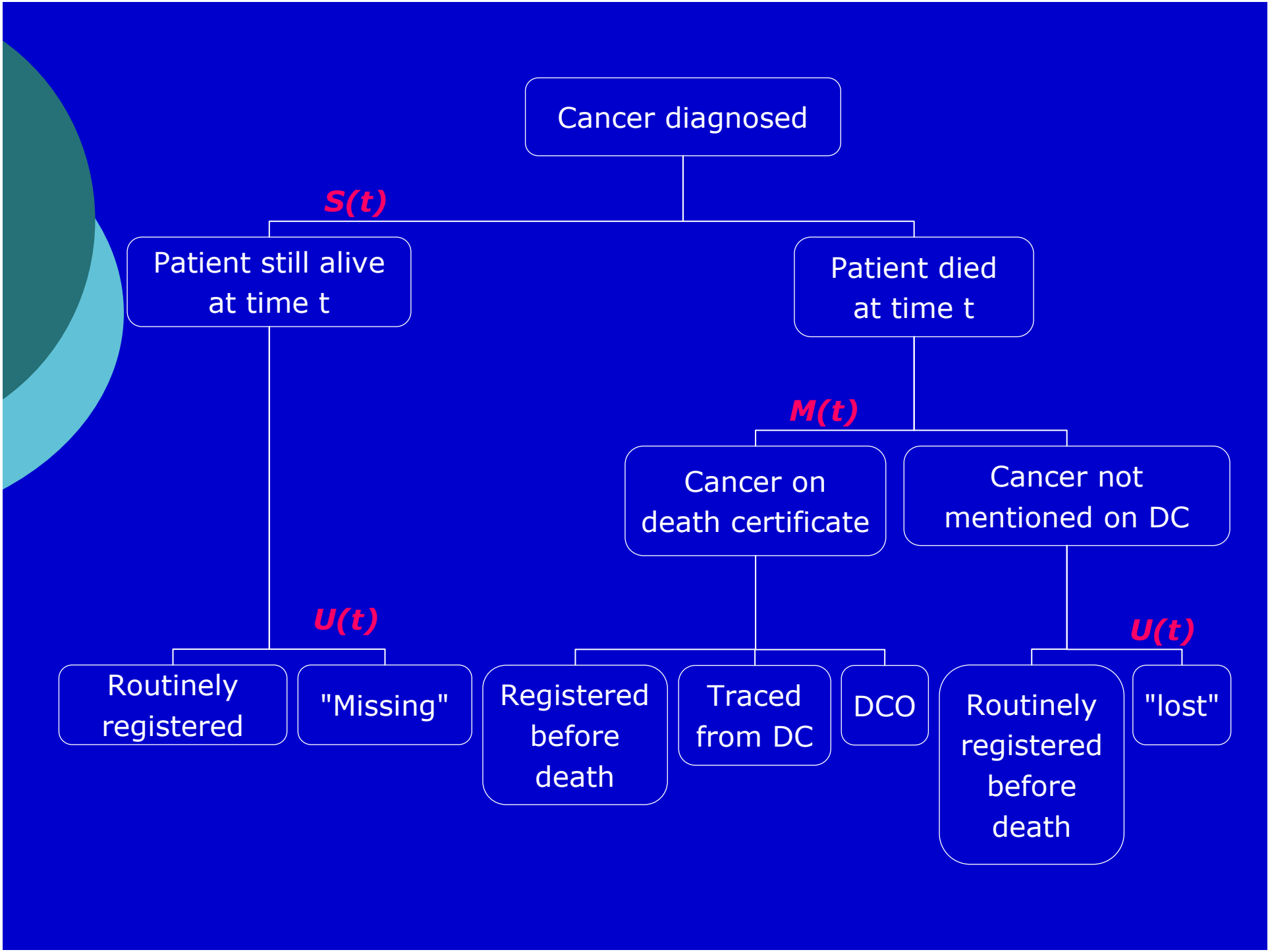
"FLOW" method

- **Basic-concept:**
  - **registration is an event observed after diagnosis**
  - **similar to any other event (e.g. death)**
  - **It can be analysed following probabilistic approach, such as survival analysis.**
- **It combines the following three time dependent probabilities**
  - **$s(t_i)$=probability that a patient diagnosed with cancer is still alive at time ti after diagnosis is obtained from the survival distribution**
  - **$m(t_i)$=probability that the death certificate of a patient who dies in the interval (t_i, t_{i+1}) includes a mention of cancer is obtained from cancer registrations of deceased patients**
  - **$u(t_i)$=probability that a patient surviving until time t_i after diagnosis is still unregistered, obtained using standard survival methods by treating registration before death as the event and censosing at death**


Cancer diagnosed
S(t)
Patient still alive at time t
U(t)
Routinely registered
"Missing"


Cancer diagnosed
Patient died at time t
M(t)
Cancer on death certificate
Registered before death
Traced from DC
DCO


Cancer diagnosed
Patient died at time t
Cancer not mentioned on DC
U(t)
Routinely registered before death
"lost"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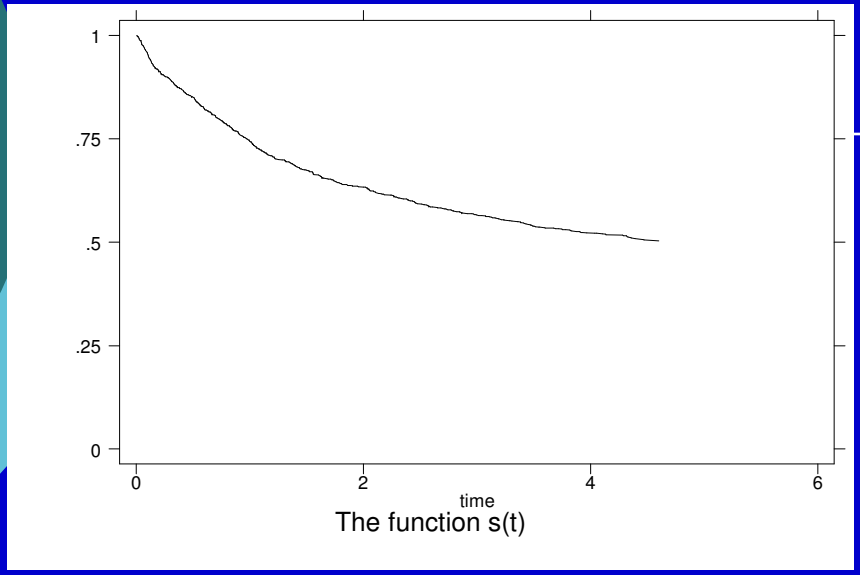
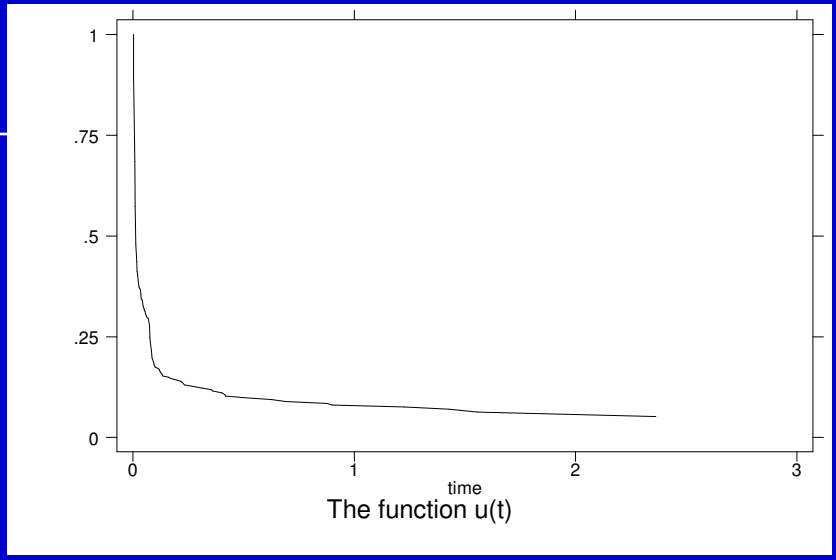
Set of Graphs provided by completeness programs

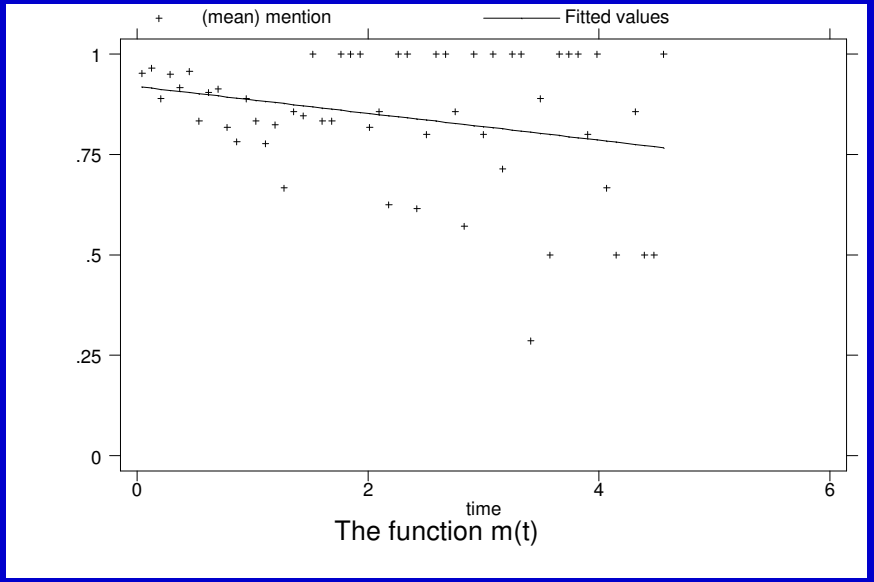
(Ex.: Ticino, All cancer sites, both sexes)



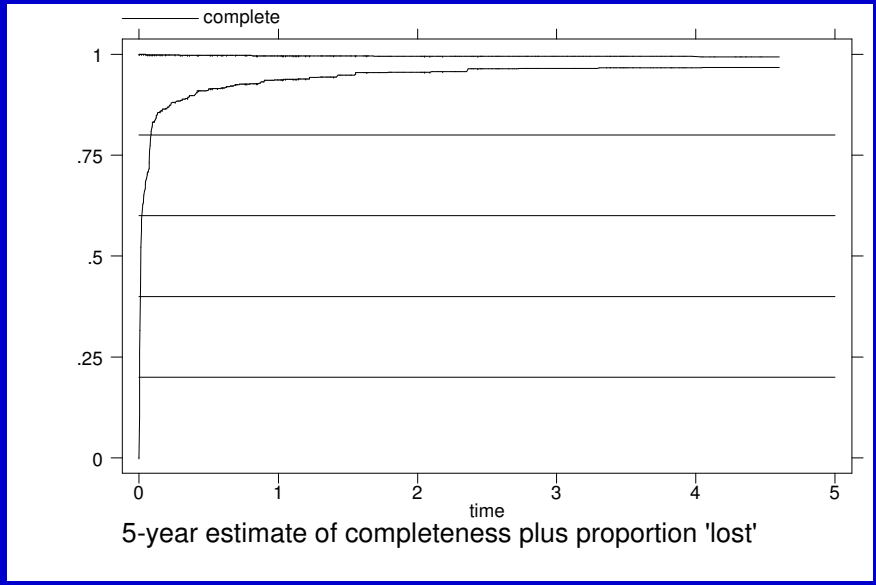
The function s(t)



The function u(t)



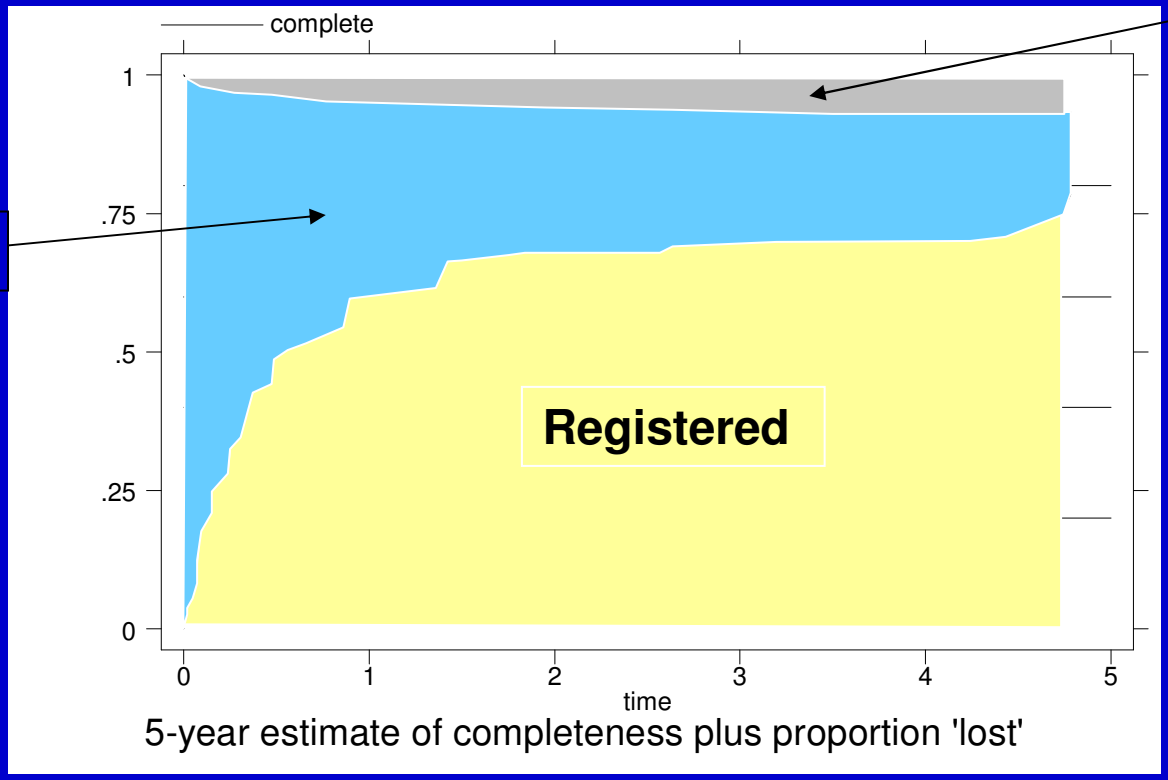
The function m(t)



5-year estimate of completeness plus proportion 'lost'

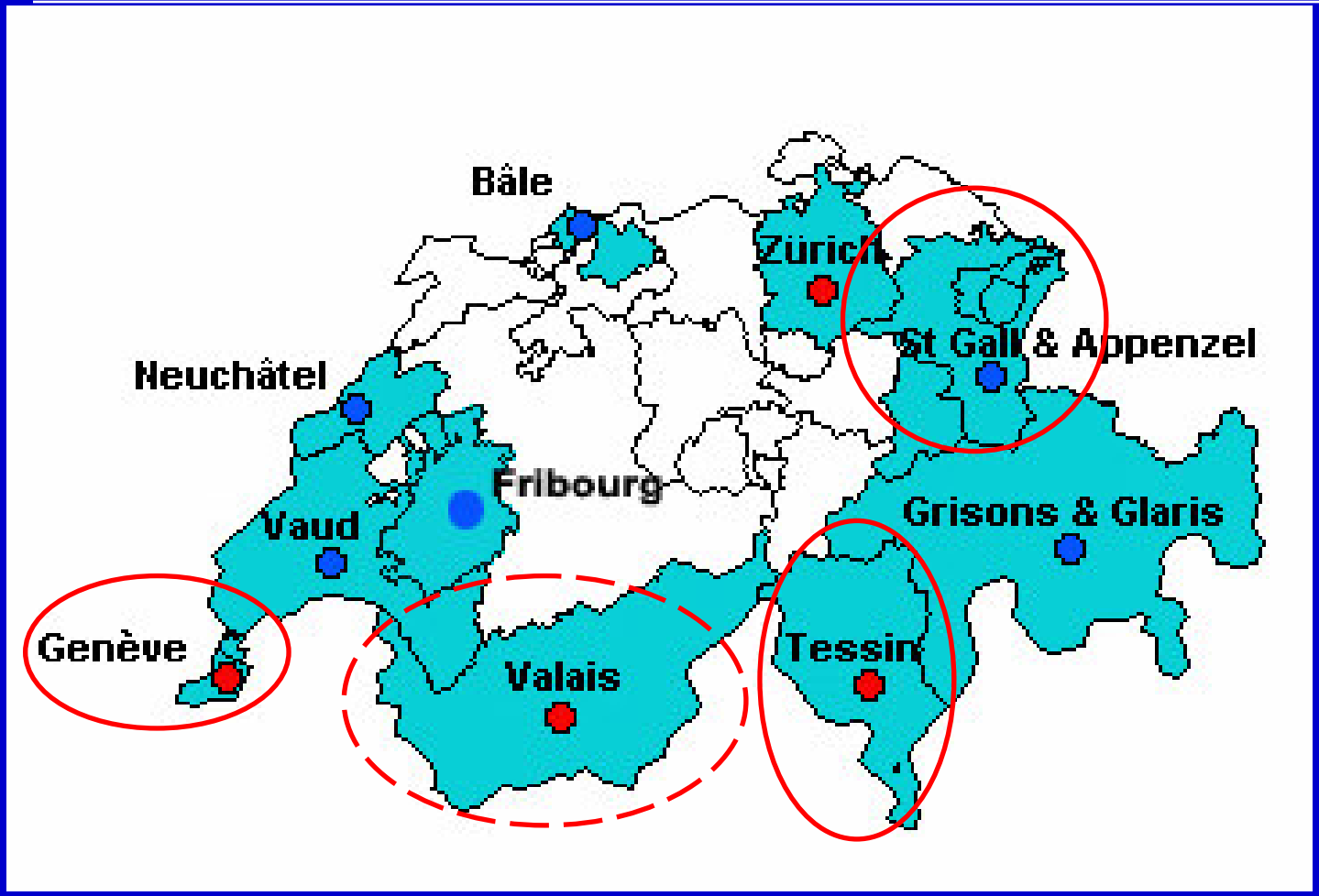
Note: results reported just as an example

Completeness of cancer registration
(Ex.: Geneva, leukemias, both sexes)



Note: results reported just as an example

The Association of Swiss Cancer Registries (ASRT/VSKR)



Analysed data

Completeness analysis was performed using two data files:

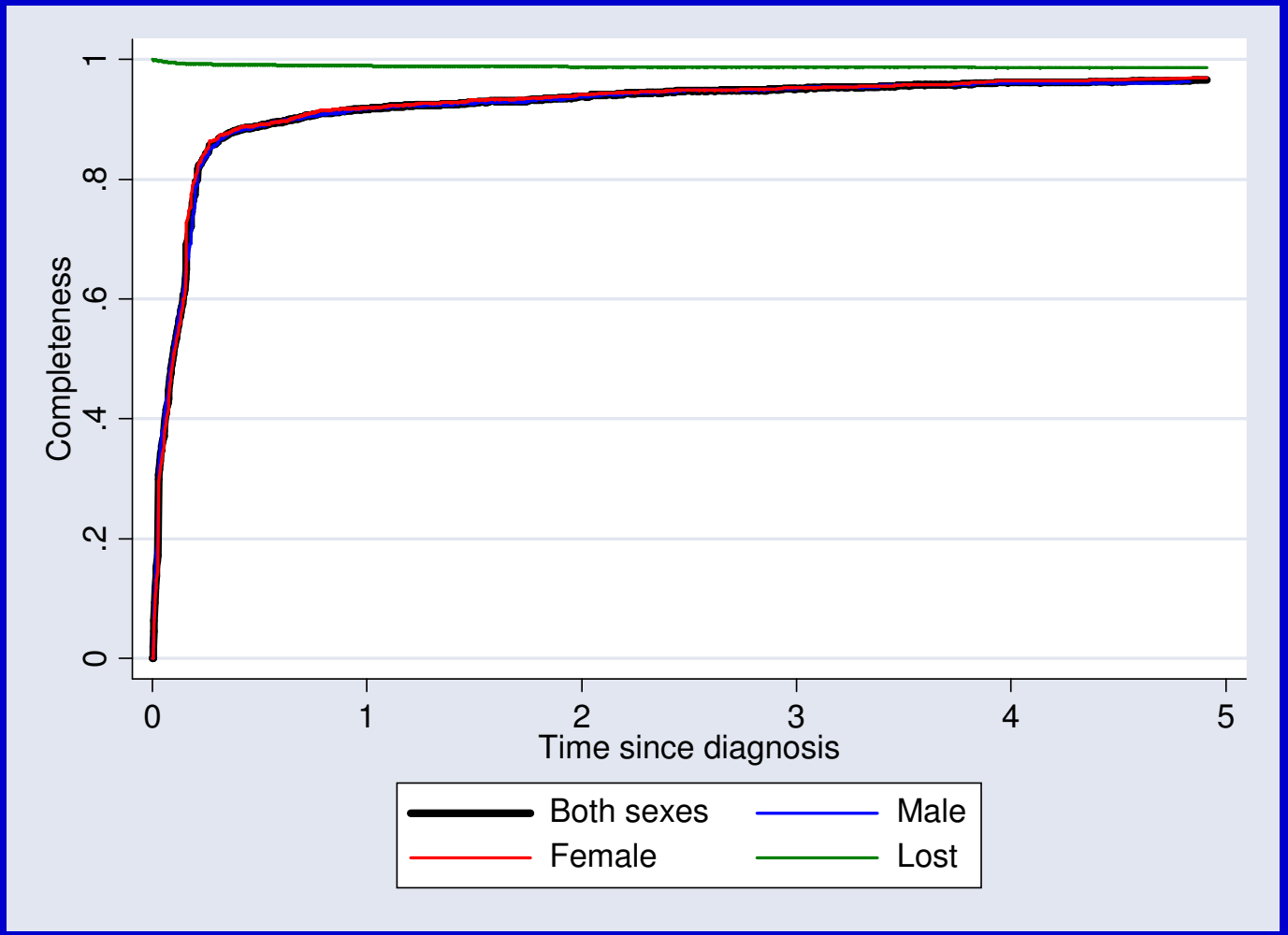
- A file containing all cancer cases diagnosed during **1996-2000** in Ticino and Geneva and during **1996** in St. Gallen (**incidence_file**)
- A file containing all cases recorded on the Registries' database who died during **2000** (**death_file**)

Completeness of Cancer Registration in Switzerland (1996-2000)

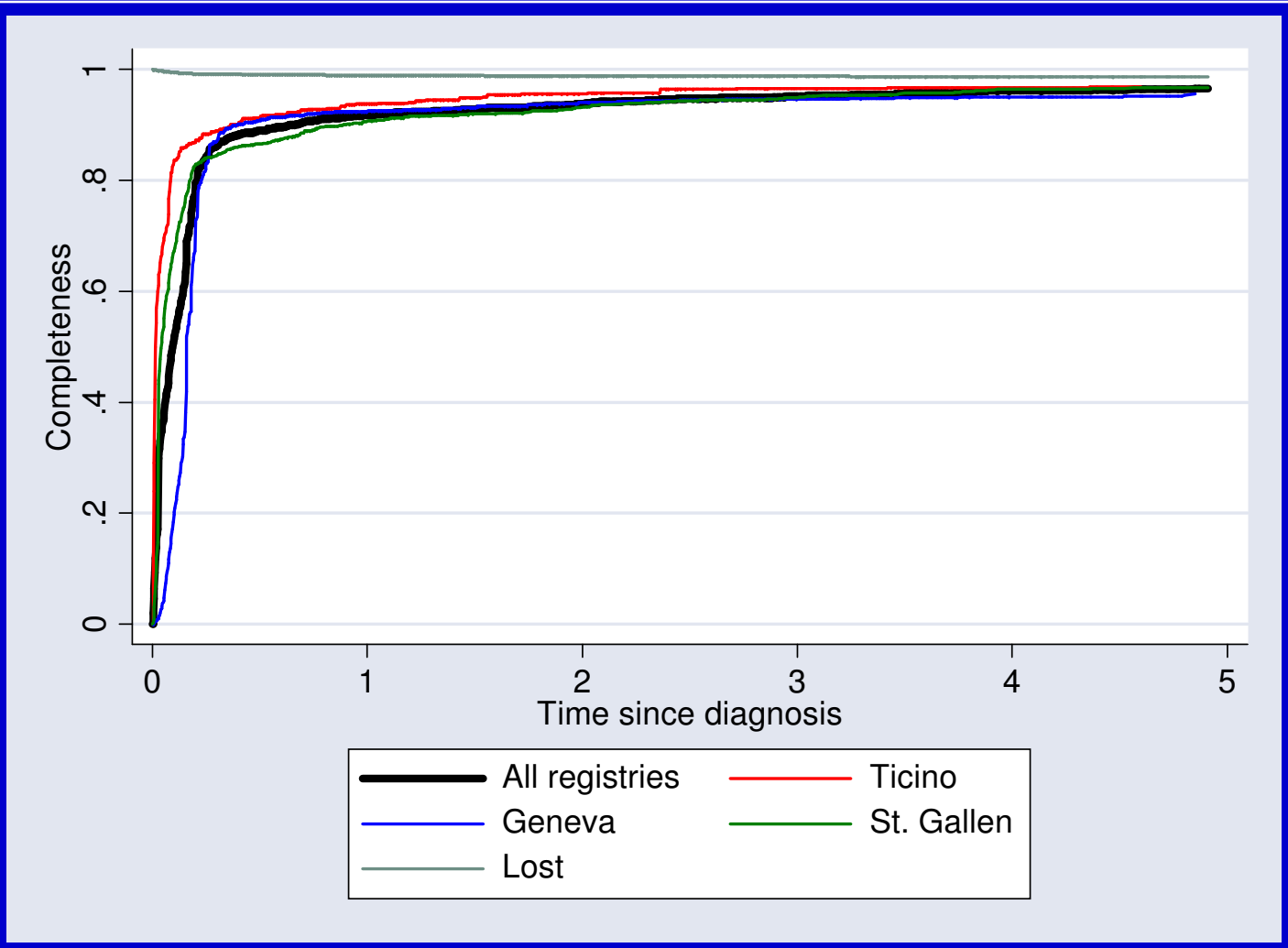
All sites but C44						
	Sex confused		Males		Females	
Time	Completeness	95% CI	Completeness	95% CI	Completeness	95% CI
1 year	0.9181	0.9027 to 0.9322	0.9184	0.8948 to 0.9393	0.9191	0.8935 to 0.9415
2 years	0.9385	0.9248 to 0.9509	0.9377	0.9183 to 0.9547	0.9409	0.9198 to 0.9591
3 years	0.9513	0.9400 to 0.9615	0.9512	0.9354 to 0.9649	0.9529	0.9350 to 0.9680
4 years	0.9618	0.9513 to 0.9710	0.9603	0.9456 to 0.9728	0.9643	0.9500 to 0.9763
5 years	0.9660	0.9535 to 0.9766	0.9637	0.9379 to 0.9828	0.9696	0.9522 to 0.9833

5-year completeness estimate

All cancer sites (but C44) by sex – All registries combined



5-year completeness estimate
All cancer sites (but C44) – By registry

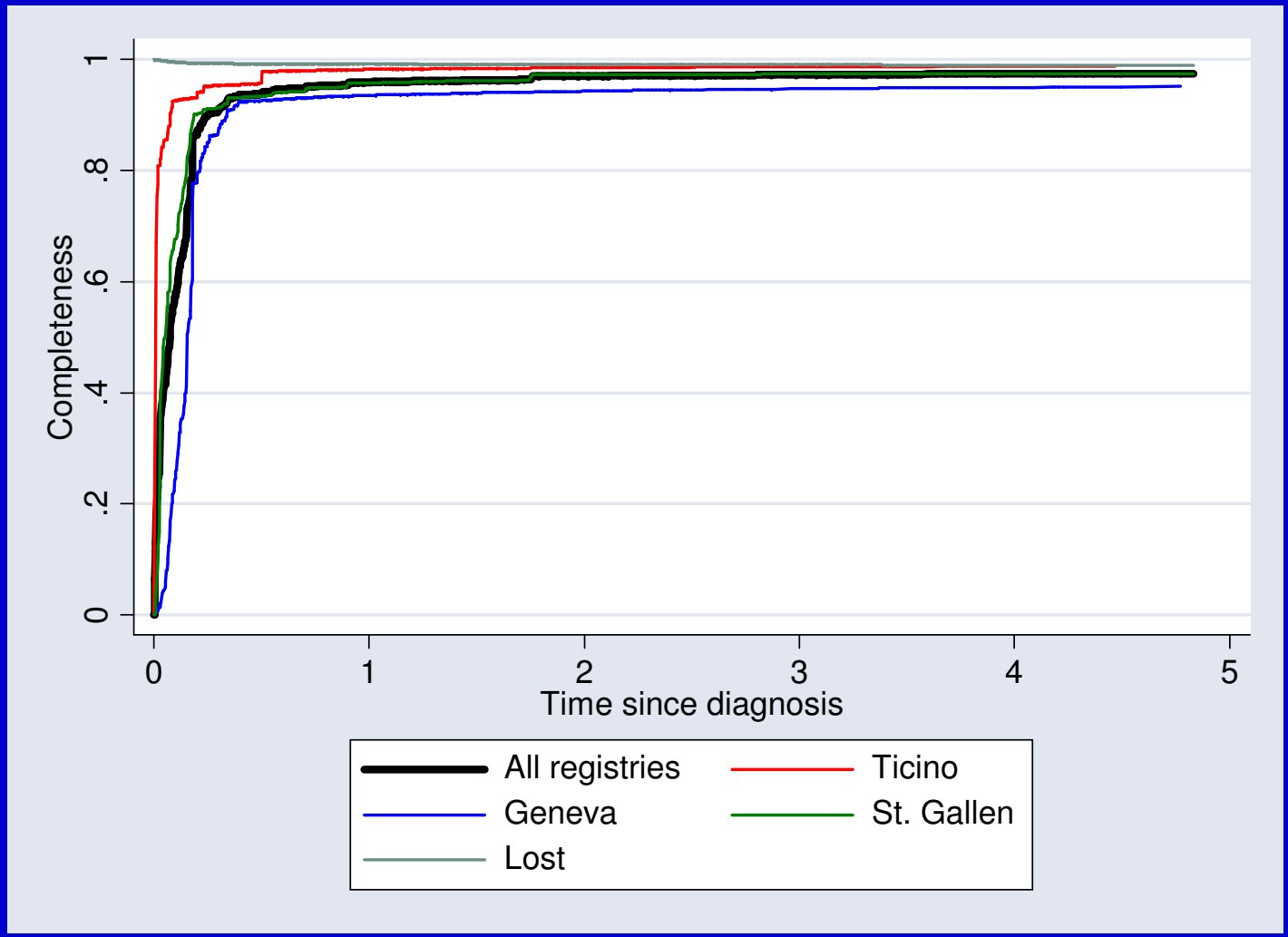


Percentiles of time (days) lagging between diagnosis and registration (1996-2000)

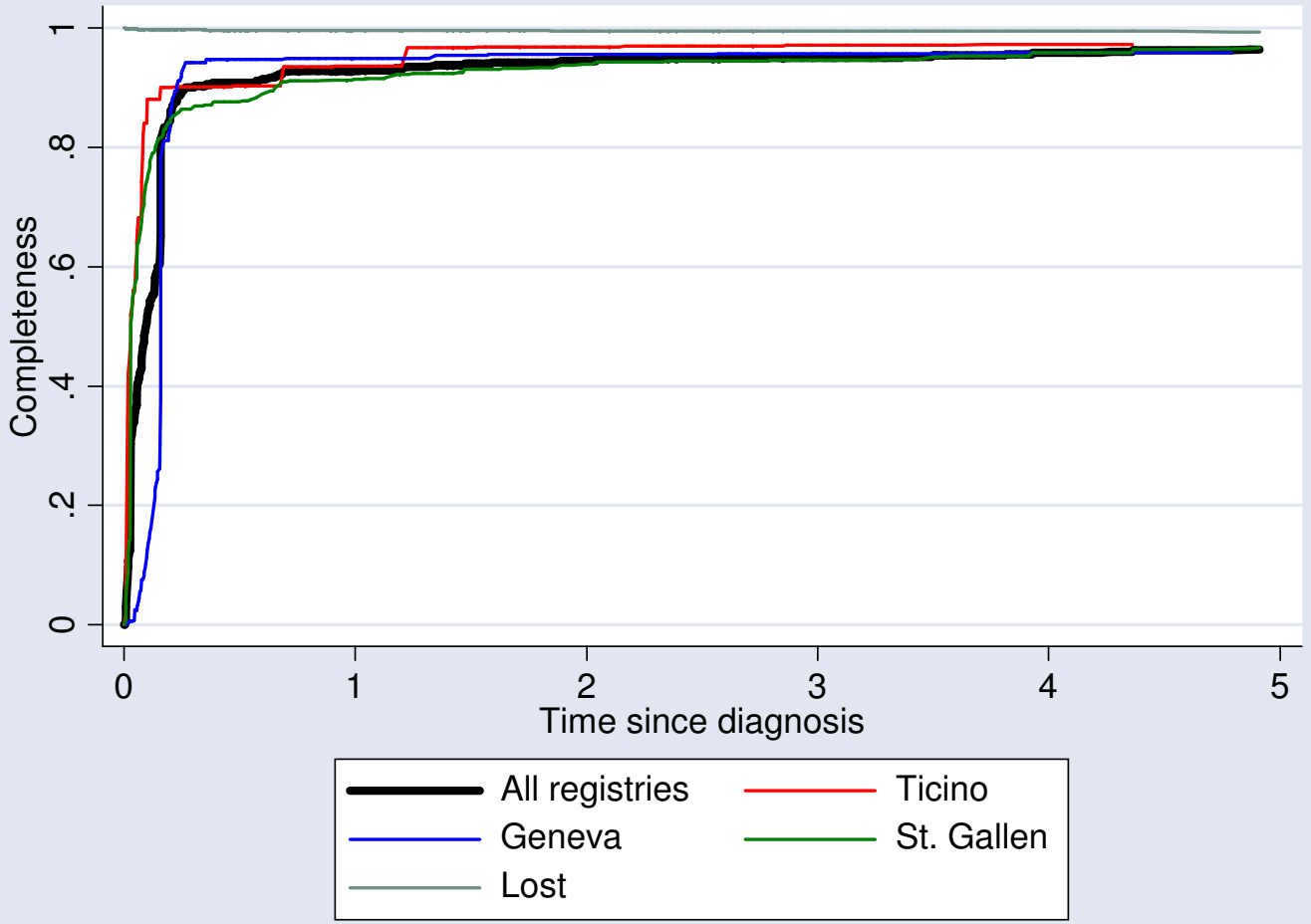
Percentiles	TI+GE+SG	TI	GE	SG
10%	4	2	27	5
25%	11	4	39	7
50%	39	9	63	13
75%	93	35	104	60
90%	418	1136	192	854

5-year completeness estimate

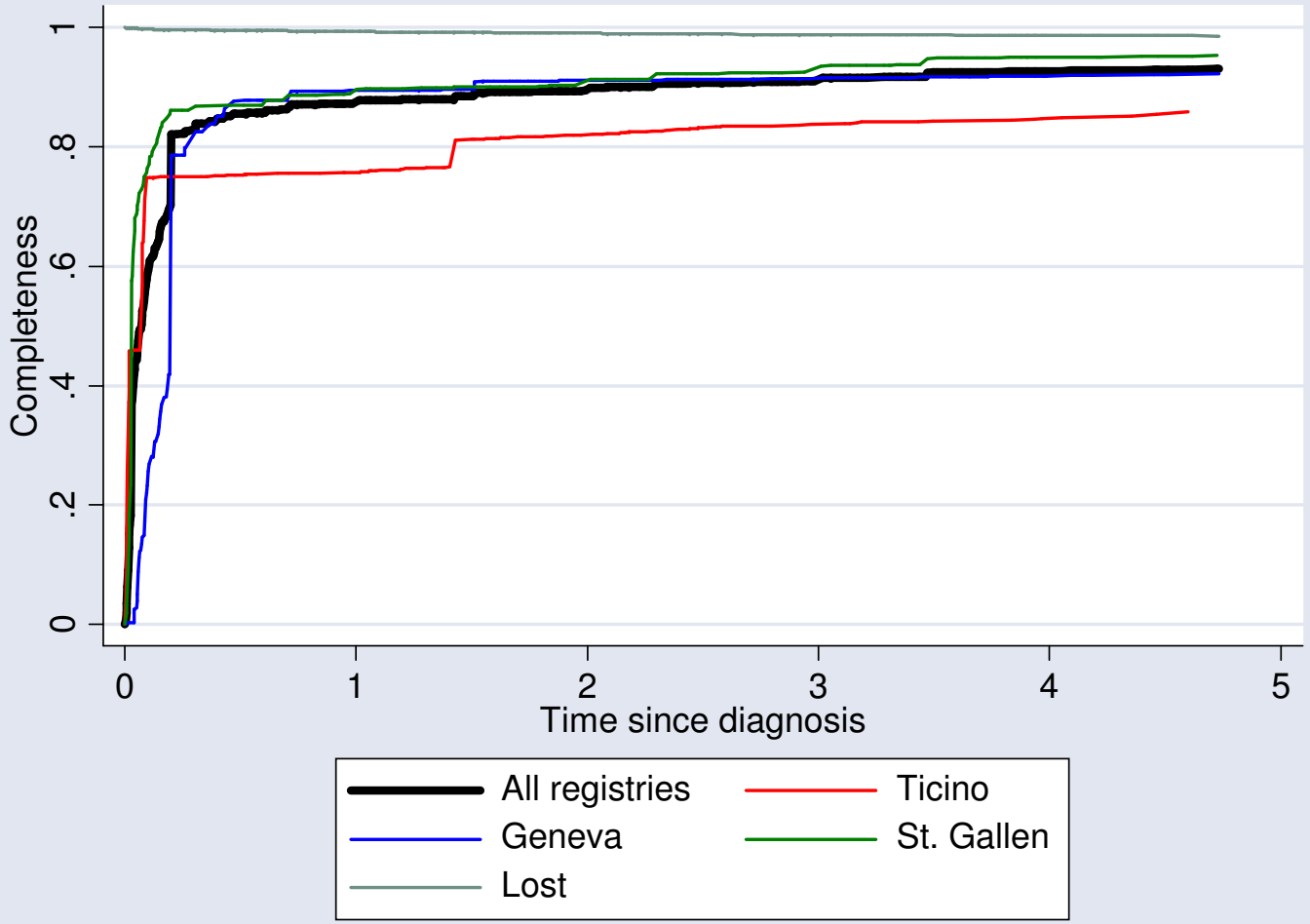
Respiratory system tumours (C30-C39) – By registry



5-year completeness estimate
Female tumours (C50-C58) – By registry

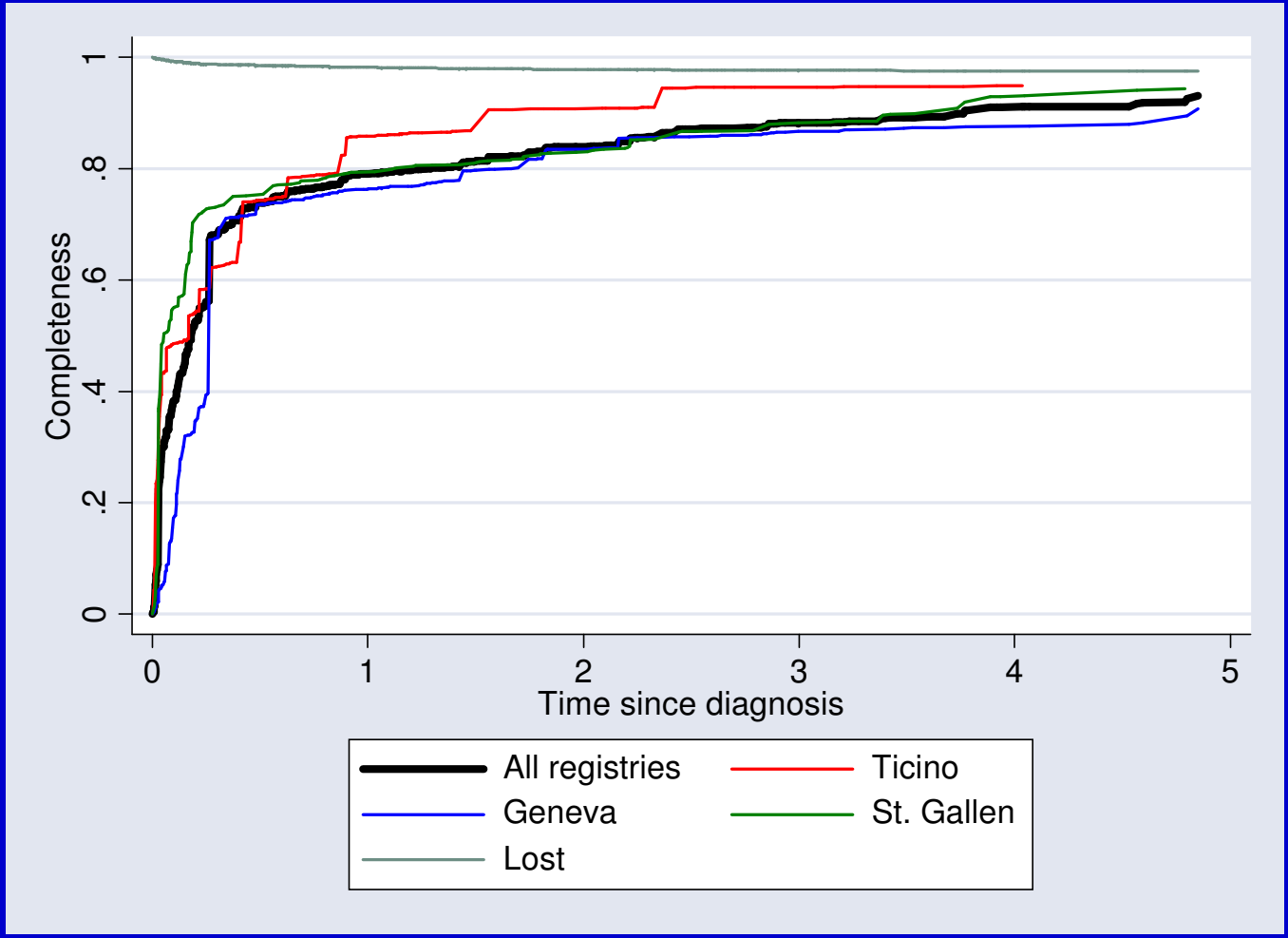


5-year completeness estimate
Male tumours (C60-C63) – By registry



5-year completeness estimate

Haematolymphopoietic system (C81-C96) – By registry



Discussion about method: main requirements

- The date when each cancer is first registered must be systematically recorded (and never changed)
- Death certificate (mortality data from OFS), mentioning cancer or not, must be received
- Follow-up must be completed at the index date, including causes of death (*problem with Valais*)
- Knowledge of whether each case is a DCI, aimed to estimate the survival time for DCOs (*optional*: DCOs can be excluded from analysis)

Discussion about results

- Globally, no difference between Swiss registries, with early completeness
- Differences among registries and by site should be investigated
- Delay in recording of some cancer sites in some registry could be "physiological" and not improvable

Conclusion

- Flow method came out as a good tool to evaluate the completeness of cancer registration (at least in Switzerland).
- Main advantage of the method: it allows to show the relationship between TIME and completeness
- Other facilities:
  - Evaluation of the quality of registration activity and identification of lacks or not expected delays
  - Estimation of readiness and reliability with which CR data could be disseminated (ex. in Switzerland, 90% of cases was registered not later than 1 year after diagnosis)