The Use of a New Completeness Measure and its Application

Description and use of the “Flow” method of Bullard et al,British Journal of Cancer, 2000

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Ron Dewar
Vickey Bu
Surveillance and Epidemiology Unit

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Estimation of Completeness of cancer registration

- No realistic ‘Gold Standard’ method
- All methods have strengths and limitations
- Look for consistency between methods, especially methods that use different assumptions or data sources

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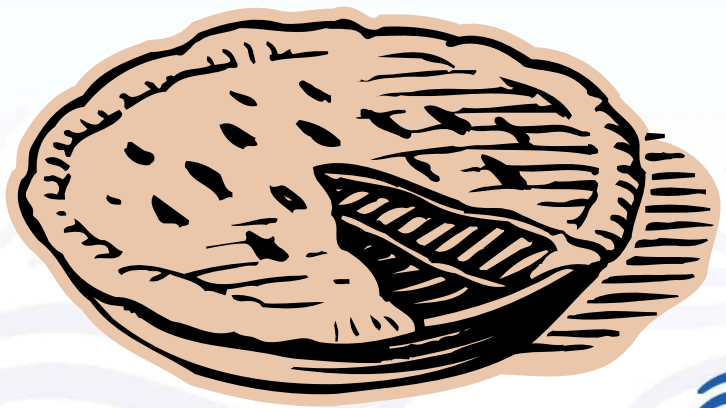

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Methods – a brief overview

- Semi-Quantitative: completeness *relative* to an external / historic standard
  - historic data methods
  - mortality:incidence ratios
  - number of sources per case
  - % histologically verified

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Methods – a brief overview (2)

Quantitative – use information about *observed* cases to estimate the number of cases that have been *unreported*

- independent case-finding
- capture-recapture
- spatio-temporal modeling
- delay adjustment / modeling
- death certificate (DC) methods
  - DC and M:I
  - 'Flow'

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Completeness

At any time after the diagnosis of cancer, cases not registered can be classified as:

- "**Missing**"– diagnosed but not yet registered. May be registered later…
- "**Lost**" – diagnosed, not registered, *deceased*, and cancer not mentioned on the death certificate (DC). Will *never* be registered.

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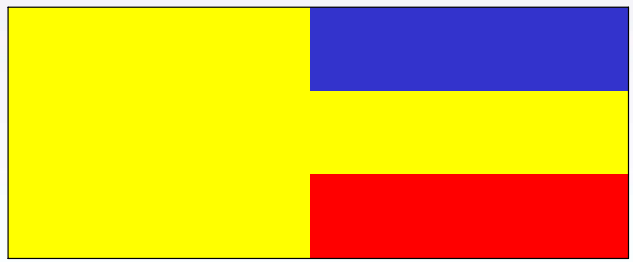
Completeness: Logical Framework

Registered ?

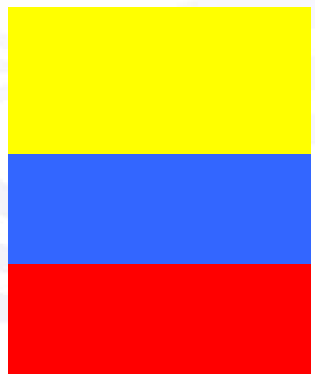
Cancer has been diagnosed and patient is …	Yes	No
Alive		
Dead - ca. on DC		
- ca. not on DC		



Registered, or will be

“Missing”

“Lost”



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Completeness

- To estimate proportion ‘Missing’ and ‘Lost’ at time *t* since diagnosis, we need time-dependent proportions:

  - survival s(t)
  - mention of cancer on DC m(t)
  - time to registration u(t)

  All estimated from *registered* patients

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Survival:
s(t): % alive at start of interval

- standard registry product
- time to event process with censoring
- requirements:
    - date of diagnosis
    - date of death (any cause)
    - end of follow-up / date last contact
    - age, sex, cancer type, etc…

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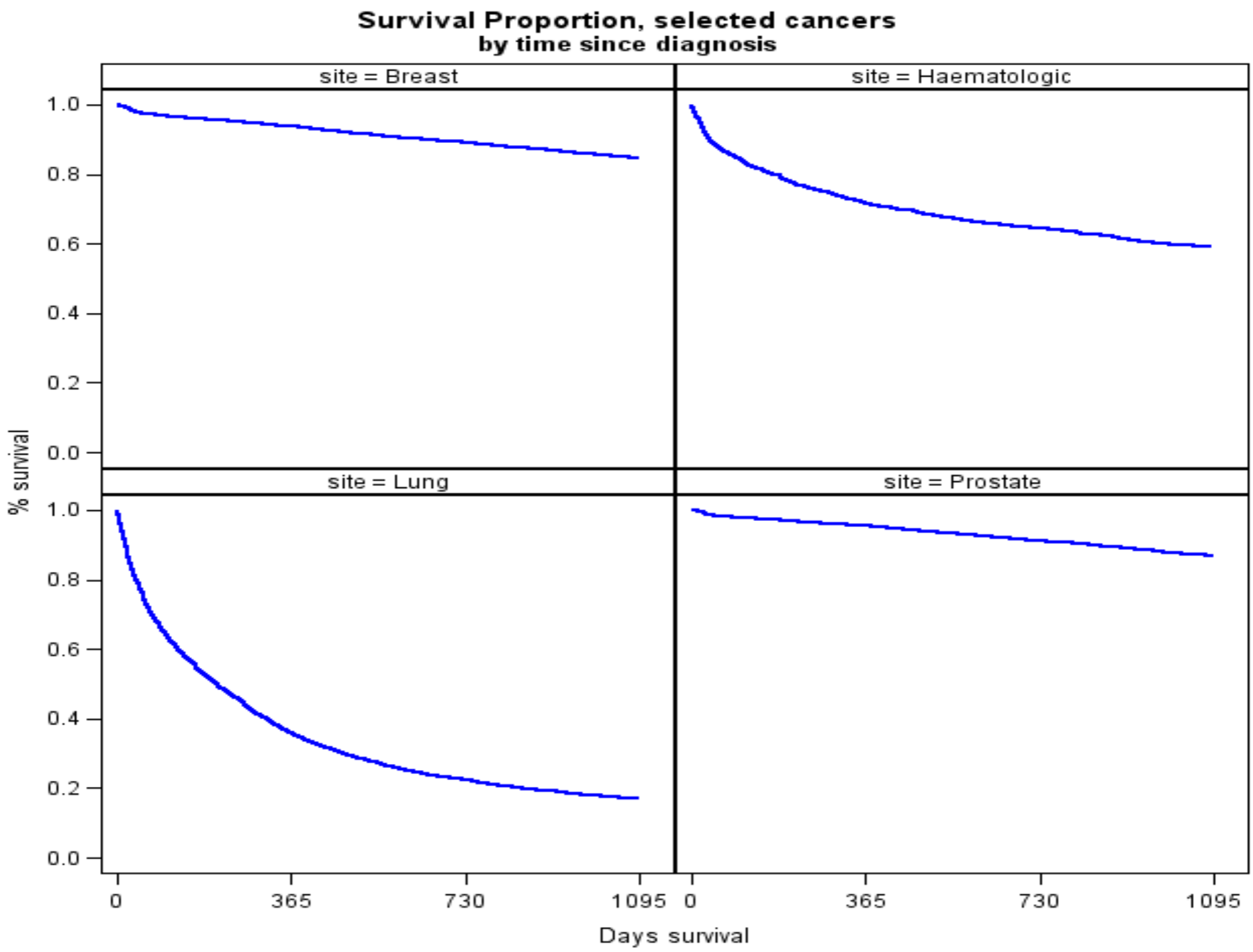
Survival Proportion, selected cancers
by time since diagnosis
site = Breast
site = Haematologic
site = Lung
site = Prostate
% survival
1.0
0.8
0.6
0.4
0.2
0.0
0
365
730
1095
Days survival

Mention:
m(t): % with cancer on DC those dying in interval

Among *registered* patients who die, what proportion have a cancer diagnosis on their DC?

Cancer may *not* be the cause of death

Requirements:

- registry receives all DCs
- note any cancer mentioned on DC
- date of diagnosis

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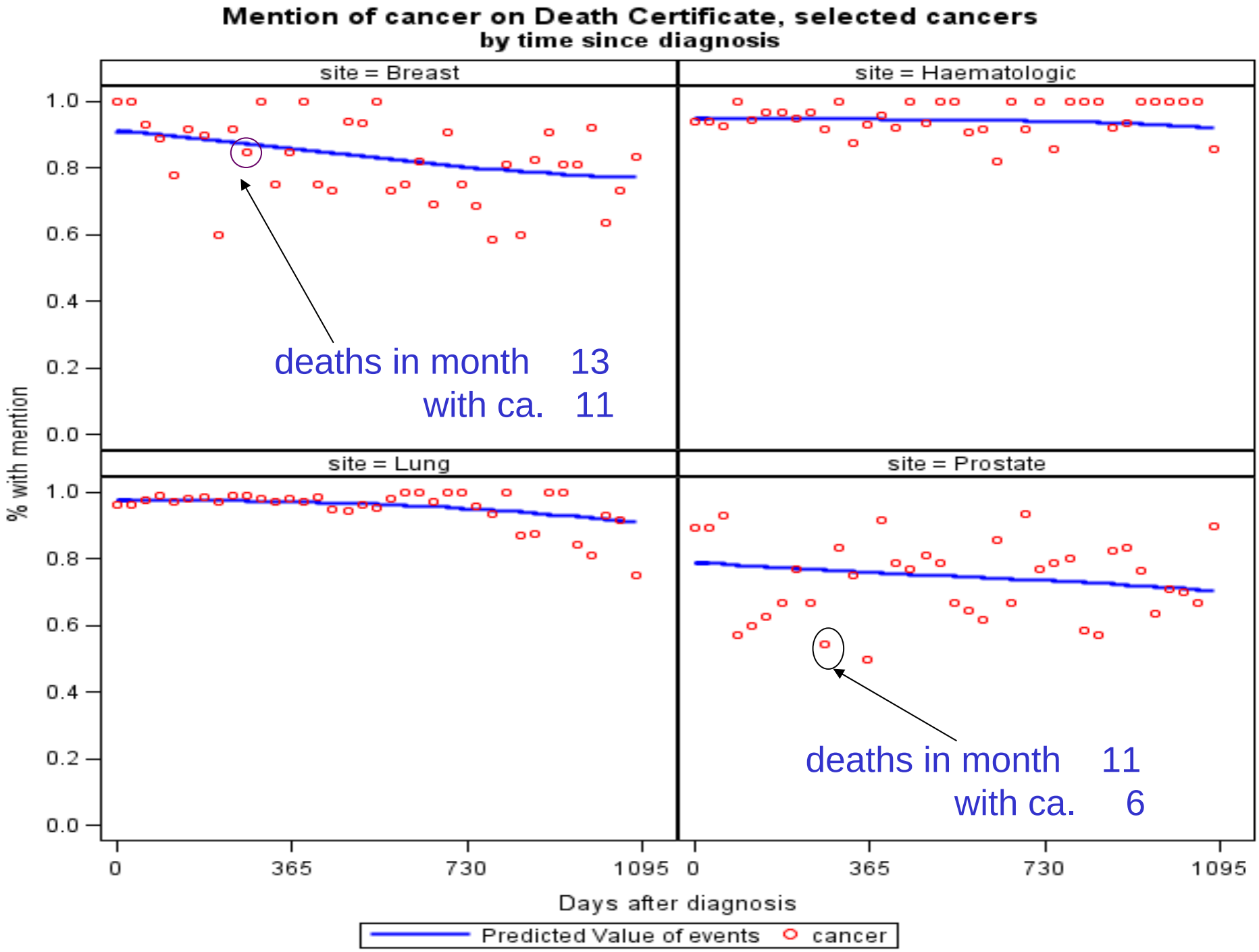
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% with mention
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0
365
730
1095
Days after diagnosis
deaths in month 13
with ca. 11
deaths in month 11
with ca. 6
Predicted Value of events
cancer

Registration
u(t): % unregistered at time t

'registration': *earliest* date the case became known, after which it would not be possible for the registry to miss the case

- not overwritten by subsequent data entry
- will depend on registry processes
- estimated from cases selected from *diagnosis* or *registration* point of view

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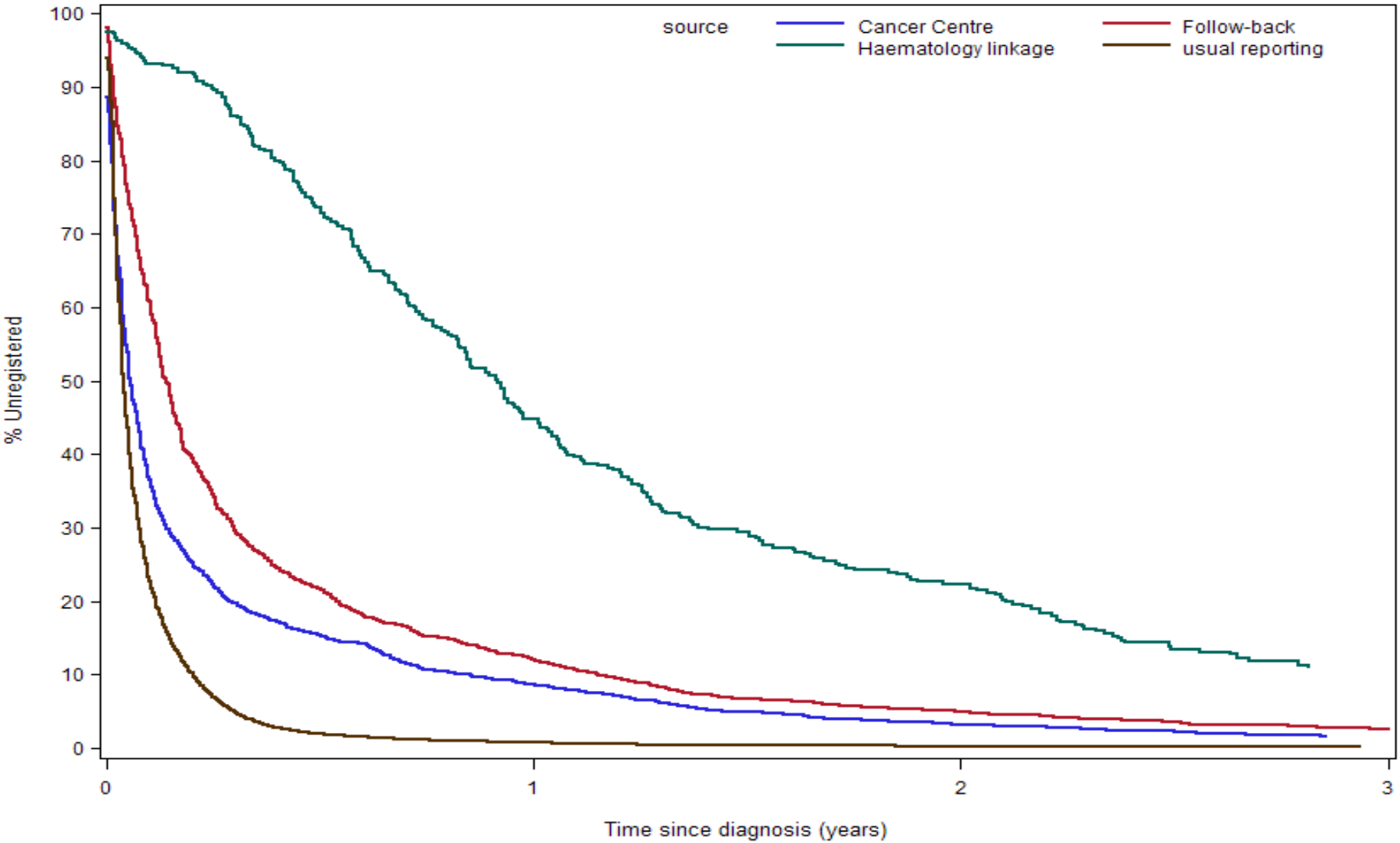
Unregistered by Time Since Diagnosis (Registration: 2002 - 2008)

by Source of Registration



Estimates at time t_i

- **Missing**: p (alive *and* unregistered)

$$= s(t_i) * u(t_i)$$

- **Lost**: p (death in interval t_i
  and not registered yet
  and cancer **not** on DC)

$$= [\, s(t_i) - s(t_{i+1}) \,] * u(t_i) * [\, 1-m(t_i) \,]$$

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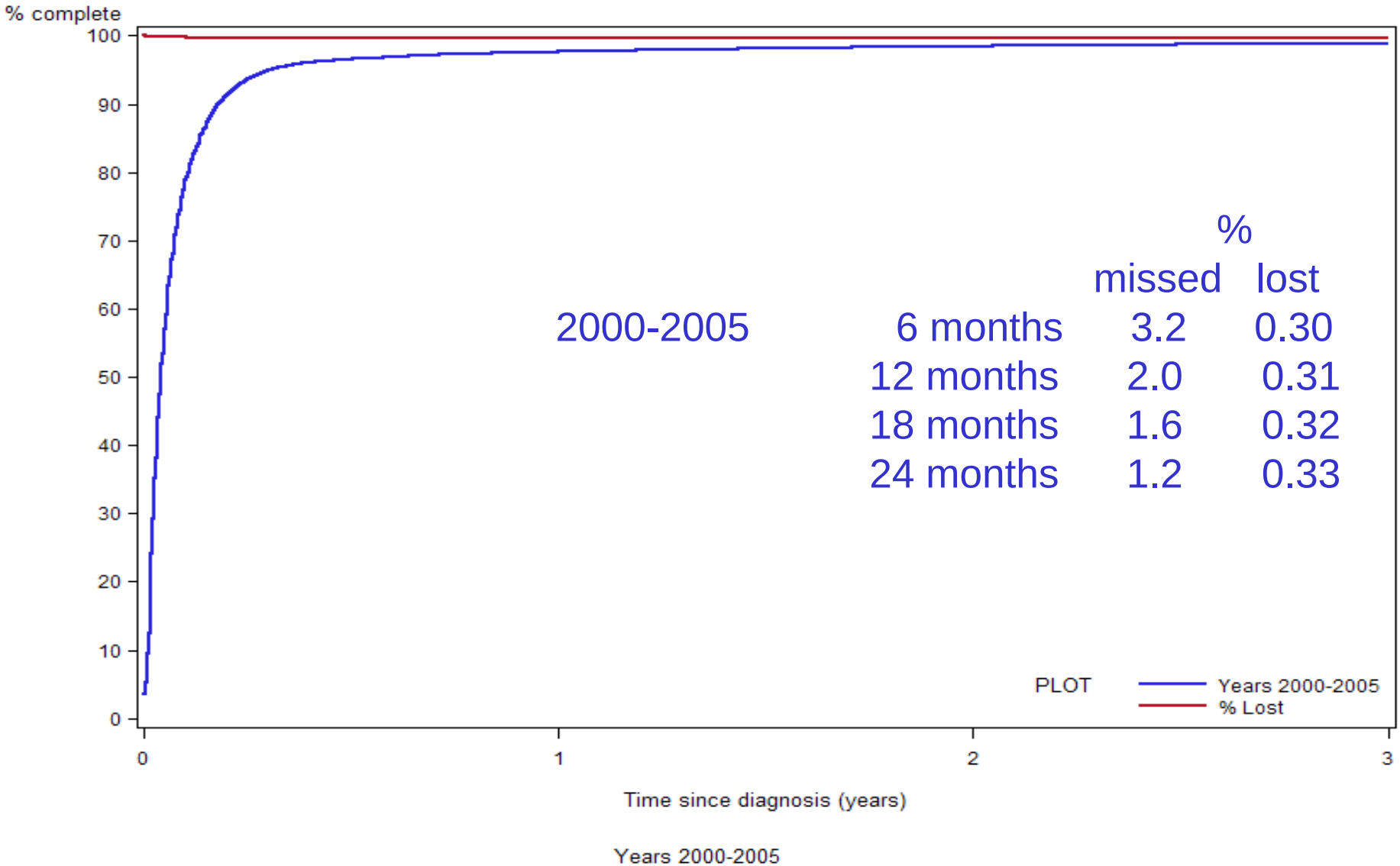
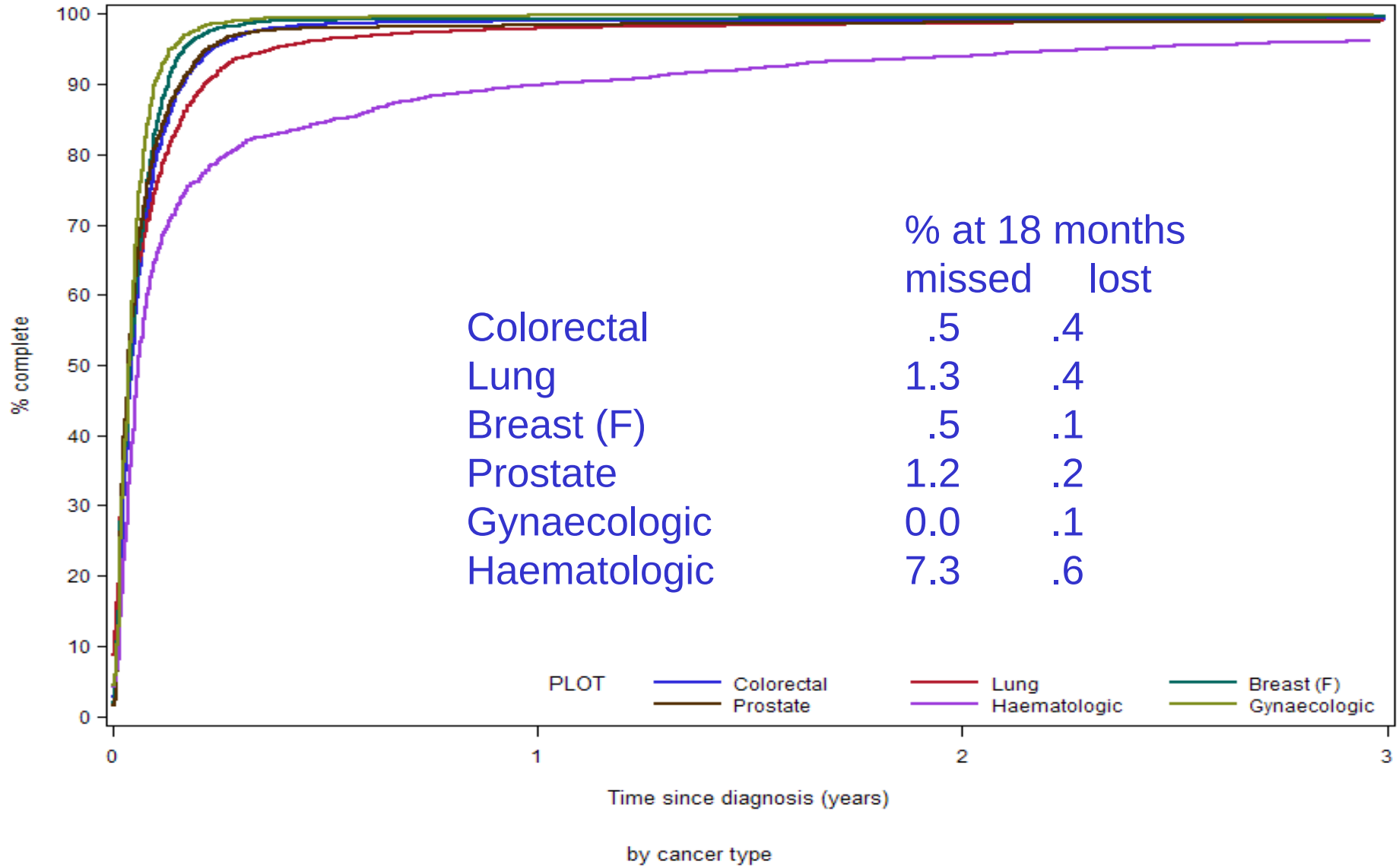
completeness by time since diagnosis



		% missed	% lost
2000-2005	6 months	3.2	0.30
	12 months	2.0	0.31
	18 months	1.6	0.32
	24 months	1.2	0.33

Years 2000-2005

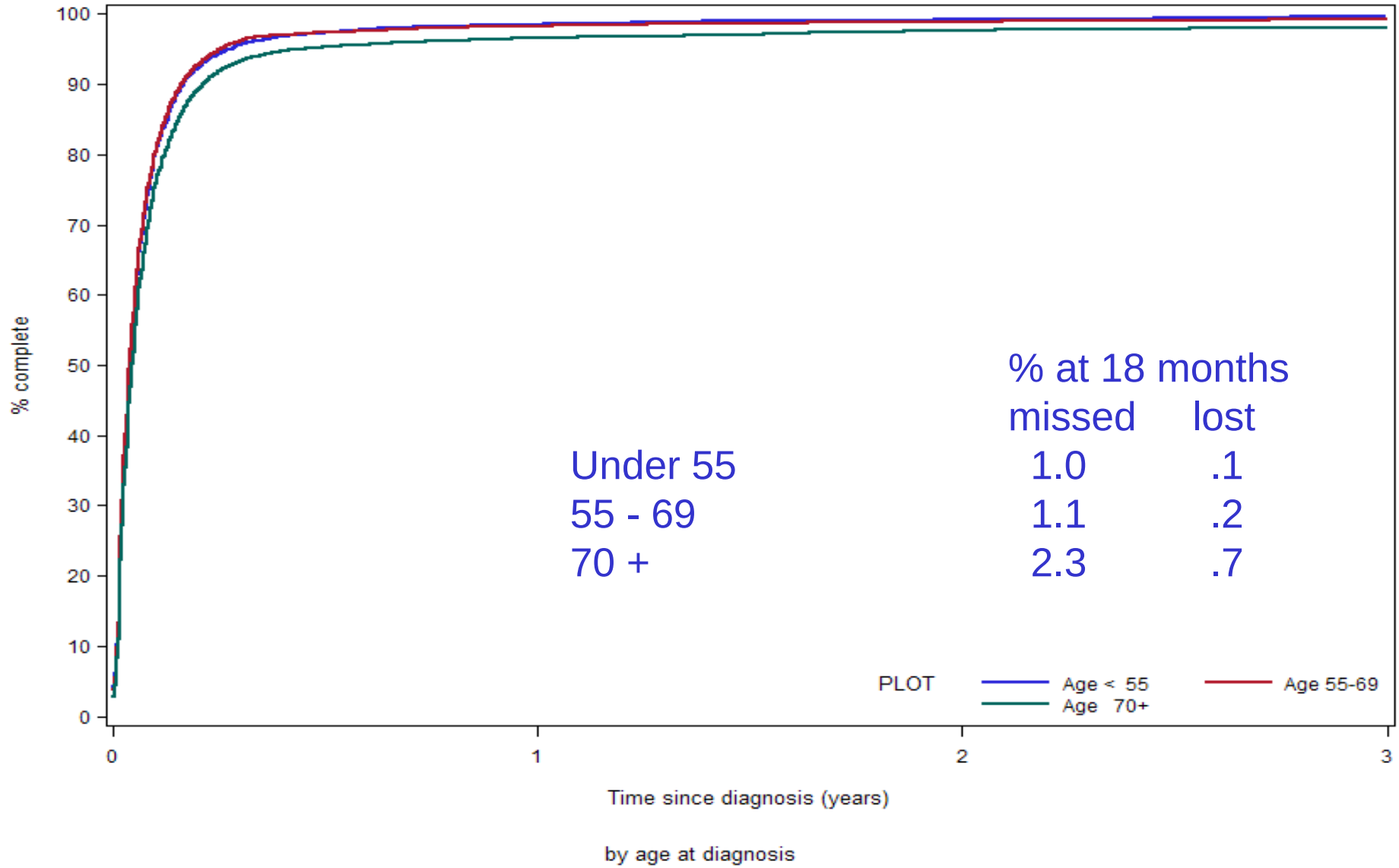
completeness by time since diagnosis



	% at 18 months missed	lost
Colorectal	.5	.4
Lung	1.3	.4
Breast (F)	.5	.1
Prostate	1.2	.2
Gynaecologic	0.0	.1
Haematologic	7.3	.6

by cancer type

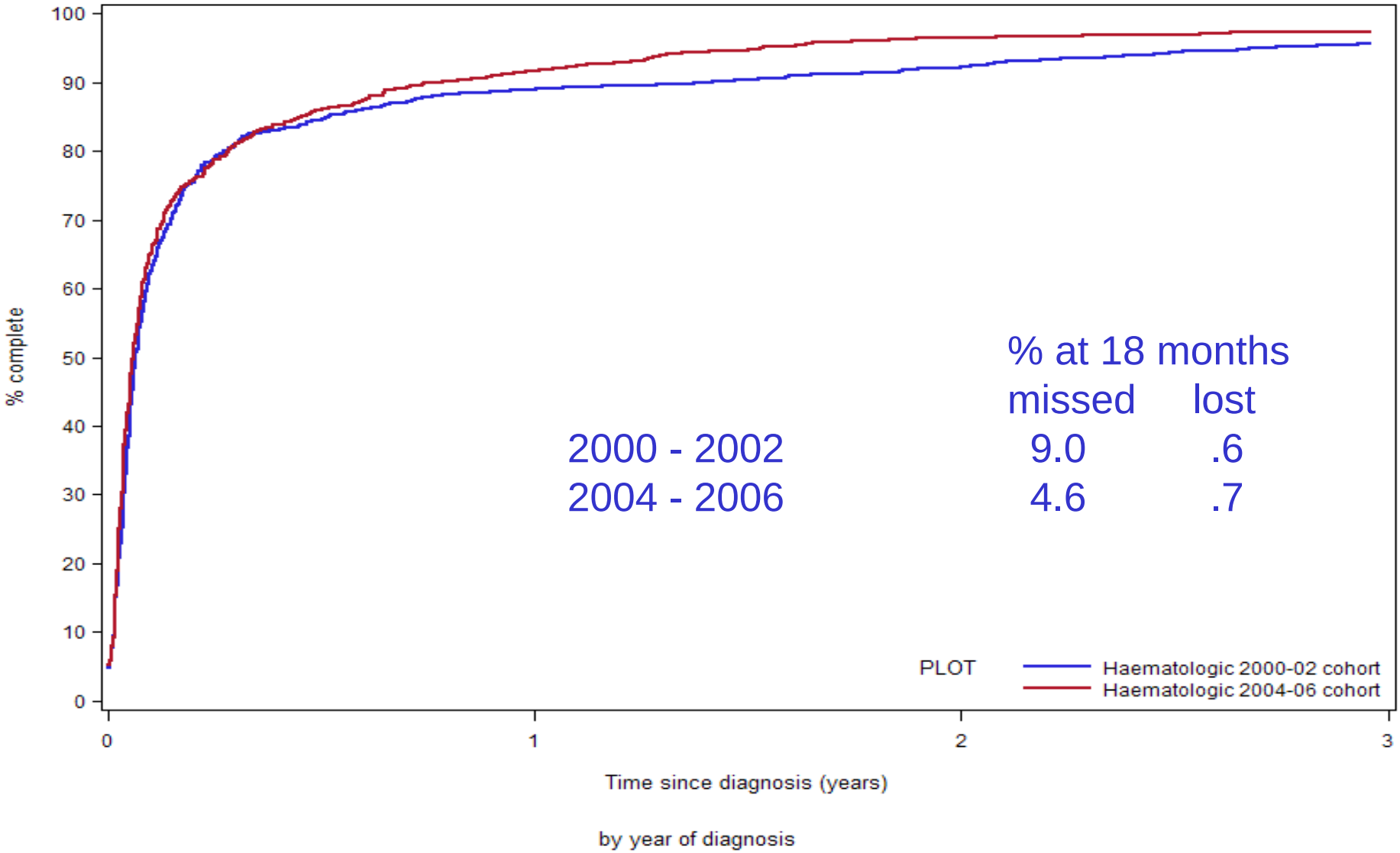
completeness by time since diagnosis



	% at 18 months missed	lost
Under 55	1.0	.1
55 - 69	1.1	.2
70 +	2.3	.7

completeness by time since diagnosis

diagnosed 2000 - 2005



	% at 18 months missed	lost
2000 - 2002	9.0	.6
2004 - 2006	4.6	.7

Completeness: ‘Flow’ method

- Extensive data, unusual programming
- Identifies situations where cases may be relatively incomplete:
  hematology, lung, older ages
- Assumptions:
  - independence of events
  - relevance of data on *registered* patients to understanding of *unregistered* patients

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Completeness: work in progress

- Time to registration is key
  - what does ‘registration’ mean?
  - all cases, or just those deceased?
- How to handle DCO and DCI cases?
  - concern where DCO or DCI % is large
- Is there a fit to NAACCR certification needs?
  - (single year’s incidence data)
- Confidence intervals?
- Effect of fatal disease on time to registration (lack of statistical independence)

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conclusions

- + estimation at any time post diagnosis
- + independent of external standard
- - data requirements
- - programming effort involved
- ? Sensitivity to failure of assumptions
- May be most useful for internal comparisons (eg, targeted ascertainment strategies)

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Completeness: take-home message

- Many methods are available
- All require a leap of faith (just different!)
- A comprehensive review of completeness should include several methods
  - internal comparisons
  - external standards

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u(t): % unregistered