

# Effect of active follow-up on survival estimates in a sample of cancer registry cases

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# Background & Introduction

- Many population-based cancer registries rely on passive follow-up to estimate survival.
- We undertook active follow-up on a sample of cases from the registry and approximated the impact that this could have on survival estimates.

# Passive follow-up

- Assumes registered persons not matched to mortality records are alive at the time-point to which all records have been completely collated.
- Enables unbiased estimates provided:
  - all deaths are properly recorded + matched
  - there is no emigration of cancer patients.

# European Registries

**EUROCOURSE** “79% use death certificate matching for vital status”<sup>1</sup>

We don't know exactly how many registries primarily rely on this...

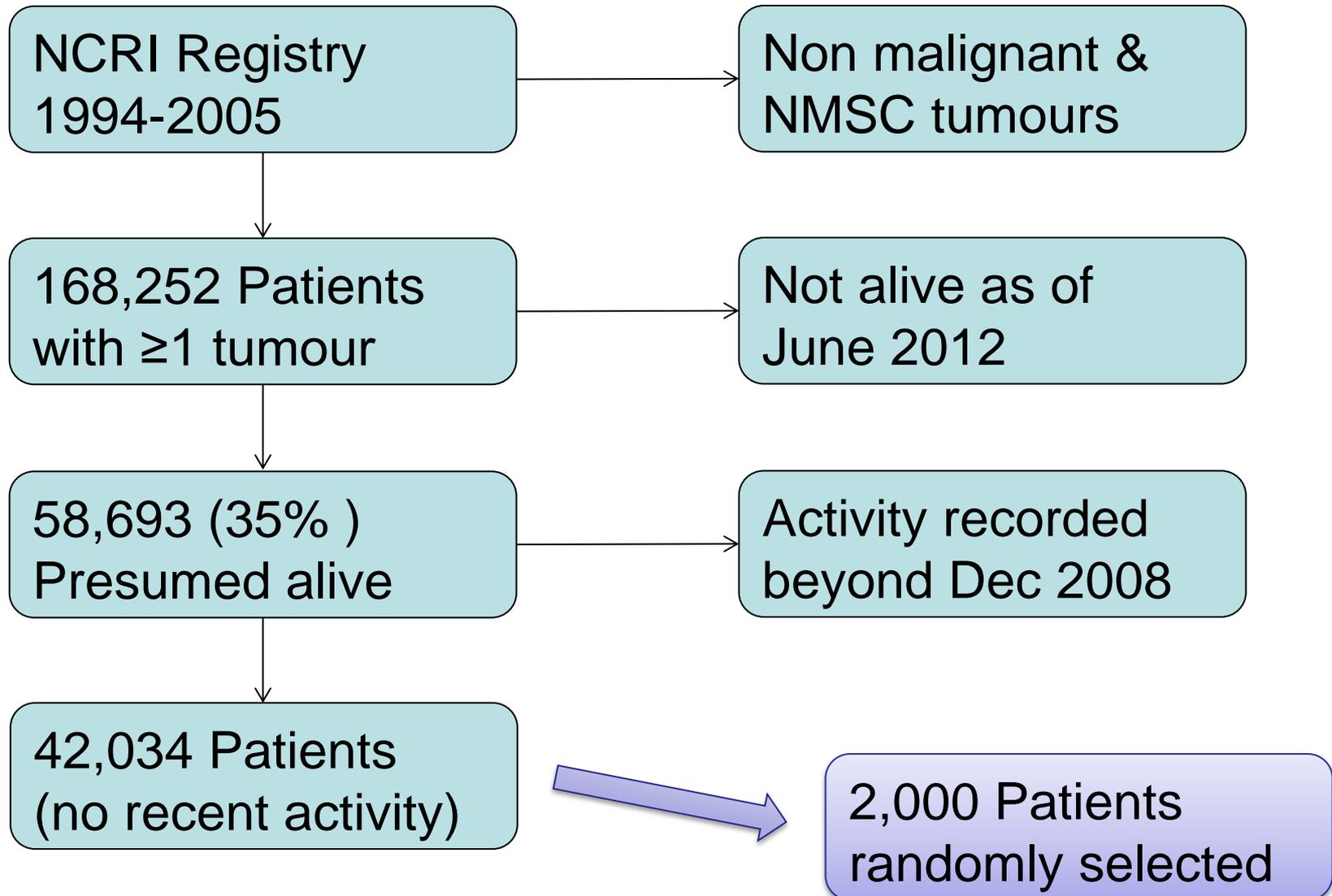
**EUROCARE 5** ~23% (27/116)<sup>2</sup>



<sup>1</sup> Dr Annemiek Kwast, NCIN presentation 2011 ([www.ncin.org.uk/view?rid=924](http://www.ncin.org.uk/view?rid=924))

<sup>2</sup> Correspondence Dr Roberta De Angelis (registries with perfect follow-up)

# Sample of alive patients



# Patients followed-up

- The status of these patients was determined by a government social security department source
- If no status, we attempted follow-up via letters to general practitioners (GPs).

# Materials & Methods

- Observed survival and follow-up distributions of the sampled cohort were computed.
- Bootstrap resampling was used to extrapolate results from the cohort and estimate the plausible impact of active follow-up compared to passive.

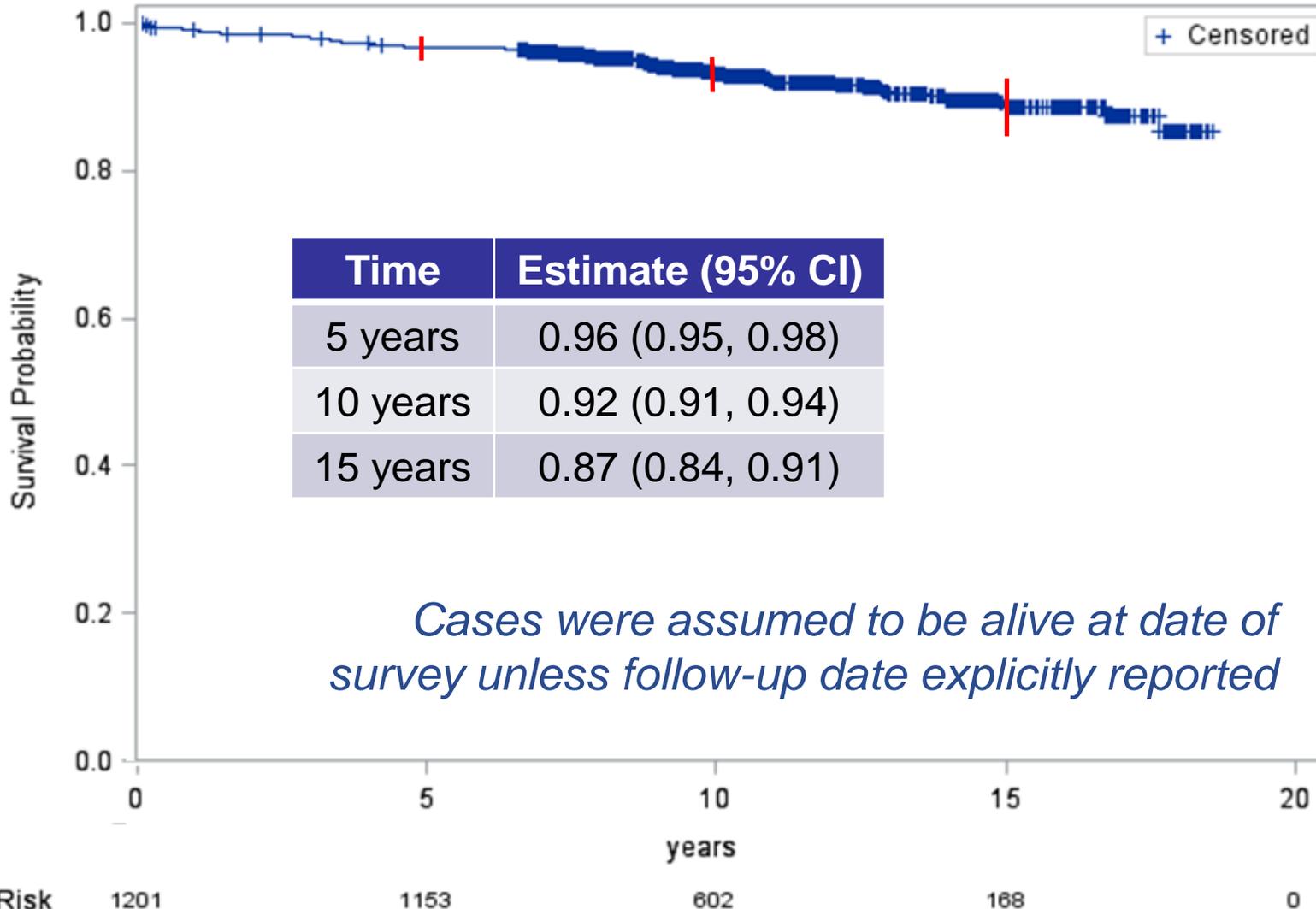
# Results

From the 2000 sampled patients an updated status was obtainable for 1244 (62%).

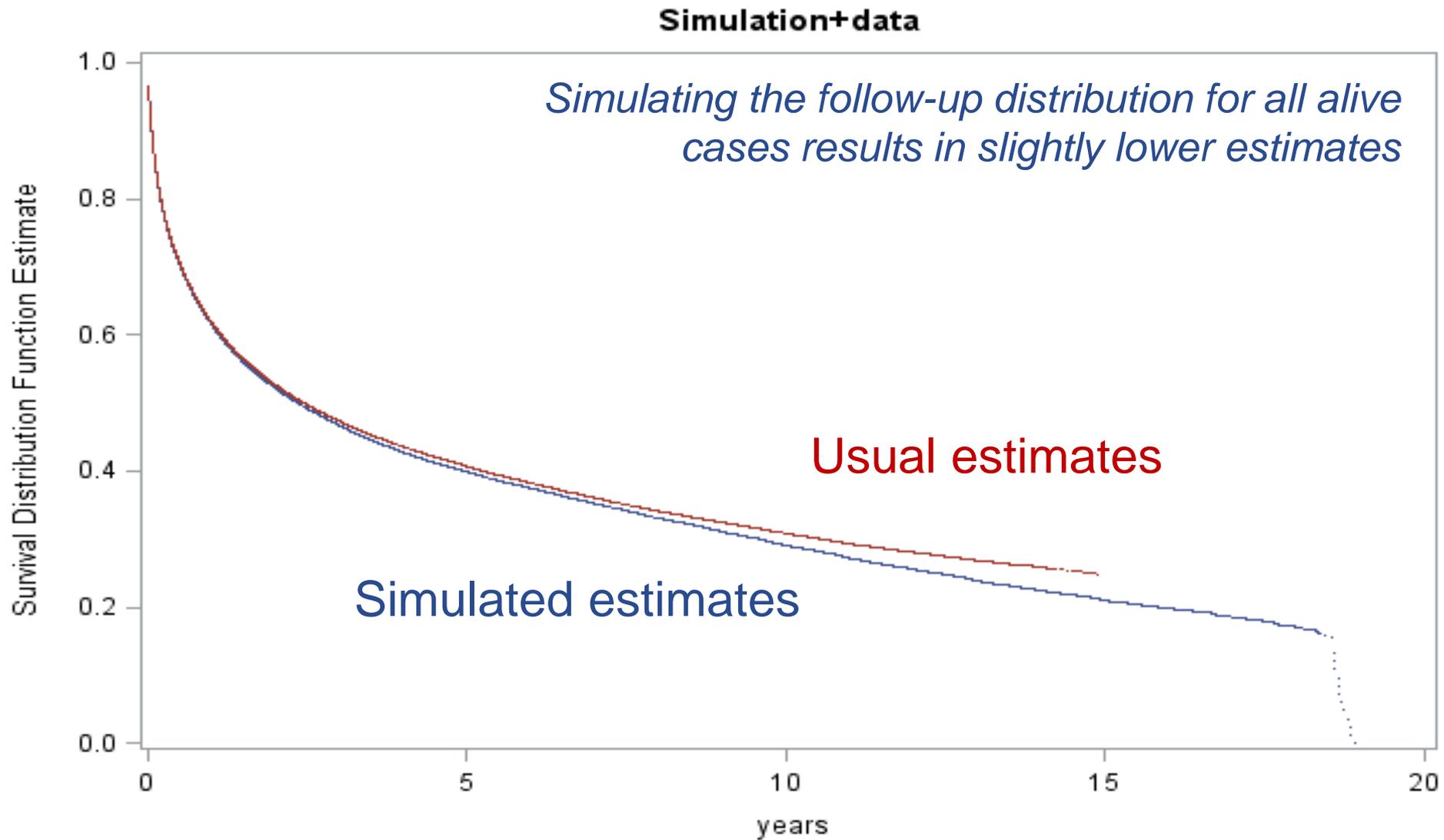
- 68 deaths reported by the department
- 52 further deaths via GPs.
- 12 cases reported as having emigrated.

# Survival distribution (sample)

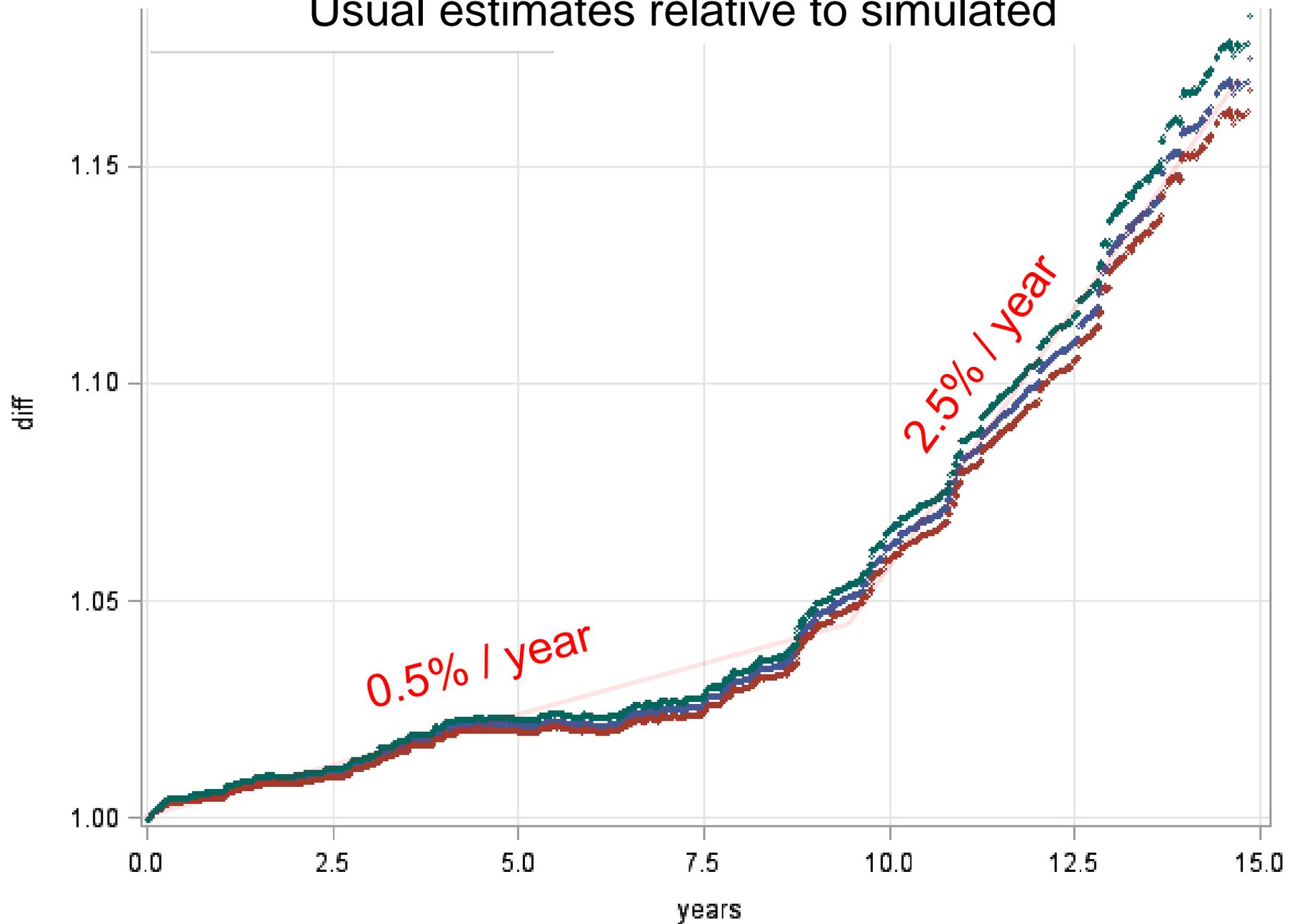
**Product-Limit Survival Estimate**  
With Number of Subjects at Risk



# Comparison of estimates

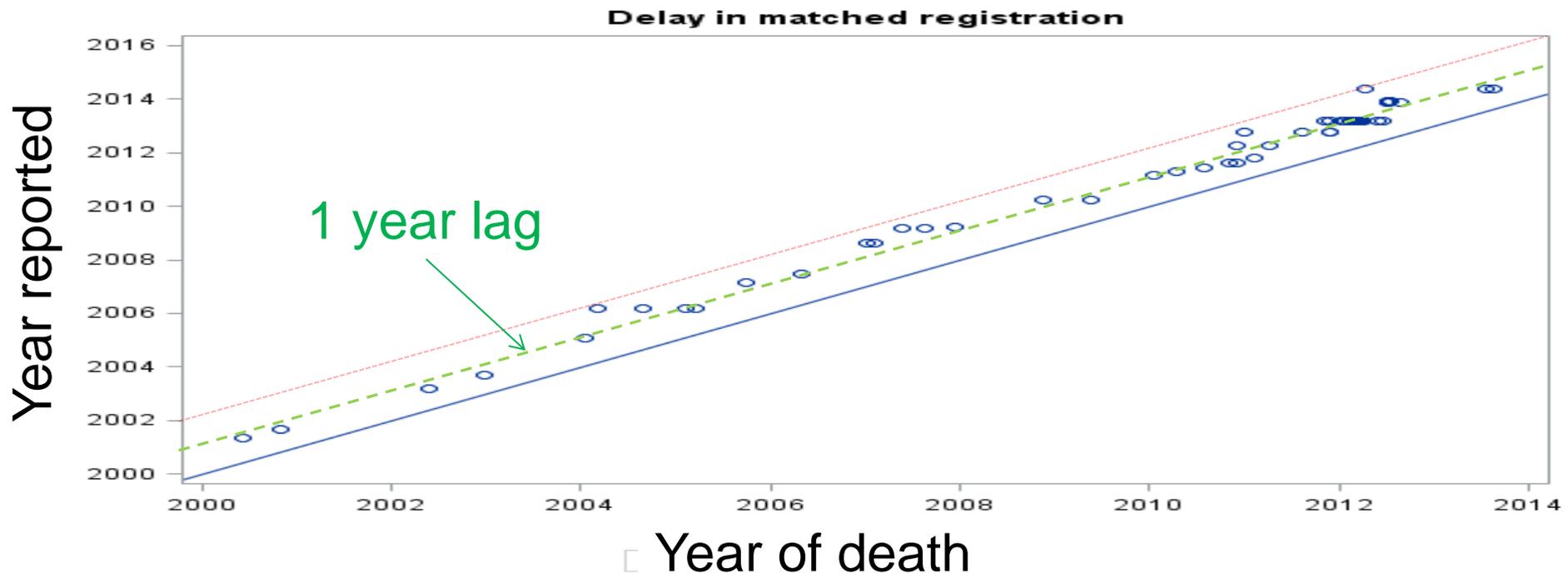


# Usual estimates relative to simulated



# Early detection

Some detected deaths would have eventually been reported through normal sources... **48% of the deaths detected have since been matched to a death certificate.**



# Can we do better?

- Targeted follow-up?
  - We are currently targeting cases:
    - With no follow-up beyond diagnosis
    - AND**
    - Aged >90 years **OR**
    - <10% survival probability for their cancer
- Pseudo-active follow-up?
  - Last known alive from all sources
    - Sources introduce biased follow-up...

# Patient driven follow-up?

- Linked electronic health records
  - Not likely in Ireland in the near future
  - EU legislation could stop access
- Can we get cancer survivors to contact us?
  - E.g. Large, open, longitudinal study
  - Requires some *incentive* to participate
  - There will *always* be people uninterested

# Conclusions

- There were a number of unreported deaths detected which result in slightly lower survival estimates.
- Some patients were detected as having emigrated & this could increase in the future.
- Active follow-up is a ***resource intensive*** process but efforts could be targeted to maximise impact.

# Discussion

If active follow-up isn't possible, can we target our efforts?

Can we adjust estimates by a correction factor?

# Acknowledgements

Staff at National Cancer Registry Ireland, in particular:

- **The data team** for planning and carrying out the active follow-up
- **Tumour registration officers** for collecting registry data
  
- Project funding from **Irish Health Research Board**

## *Further information:*

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