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

Chris Brown, Tracy Kelleher, Fiona Dwane, Paul M Walsh, Mary Chambers, Linda Sharp, Harry Comber

National Cancer Registry Ireland
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” \(^1\)

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

EUROCARE 5 \(\sim 23\% (27/116) \) \(^2\)

\(^1\) Dr Annemiek Kwast, NCIN presentation 2011 (www.ncin.org.uk/view?rid=924)
\(^2\) Correspondence Dr Roberta De Angelis (registries with perfect follow-up)
Sample of alive patients

NCRI Registry 1994-2005

168,252 Patients with ≥1 tumour

58,693 (35%) Presumed alive

42,034 Patients (no recent activity)

Non malignant & NMSC tumours

Not alive as of June 2012

Activity recorded beyond Dec 2008

2,000 Patients randomly selected
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)

Cases were assumed to be alive at date of survey unless follow-up date explicitly reported

<table>
<thead>
<tr>
<th>Time</th>
<th>Estimate (95% CI)</th>
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<tbody>
<tr>
<td>5 years</td>
<td>0.96 (0.95, 0.98)</td>
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<tr>
<td>10 years</td>
<td>0.92 (0.91, 0.94)</td>
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Comparison of estimates

Simulating the follow-up distribution for all alive cases results in slightly lower estimates

Usual estimates

Simulated estimates
Usual estimates relative to simulated

- 0.5% / year
- 2.5% / year
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:
    o With no follow-up beyond diagnosis
    AND
    o Aged >90 years OR
    o <10% survival probability for their cancer

• Pseudo-active follow-up?
  ➢ Last known alive from all sources
    o 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.
If active follow-up isn’t possible, can we target our efforts?

Can we adjust estimates by a correction factor?
Acknowledgements

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*Further information:*

  - c.brown@ncri.ie
  - @CStatsAU
  - @IrishCancerReg

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