EVALUATING COMPLETENESS OF CANCER REGISTRATION IN SWITZERLAND

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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)

“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 $t_i$ 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"
Cancer diagnosed

$S(t)$

Patient still alive at time $t$

$U(t)$

Routinely registered

"Missing"

Registered before death

Traced from DC

DCO

Cancer not mentioned on DC

$M(t)$

Cancer on death certificate

$U(t)$

Routinely registered before death

"lost"
The function $s(t)$

The function $u(t)$

The function $m(t)$

5-year estimate of completeness plus proportion 'lost'

Set of Graphs provided by completeness programs
(Ex.: Ticino, All cancer sites, both sexes)

Note: results reported just as an example
Completeness of cancer registration
(Ex.: Geneva, leukemias, both sexes)

5-year estimate of completeness plus proportion 'lost'

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)

<table>
<thead>
<tr>
<th>Time</th>
<th>Completeness</th>
<th>95% CI</th>
<th>Completeness</th>
<th>95% CI</th>
<th>Completeness</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 year</td>
<td>0.9181</td>
<td>0.9027 to 0.9322</td>
<td>0.9184</td>
<td>0.8948 to 0.9393</td>
<td>0.9191</td>
<td>0.8935 to 0.9415</td>
</tr>
<tr>
<td>2 years</td>
<td>0.9385</td>
<td>0.9248 to 0.9509</td>
<td>0.9377</td>
<td>0.9183 to 0.9547</td>
<td>0.9409</td>
<td>0.9198 to 0.9591</td>
</tr>
<tr>
<td>3 years</td>
<td>0.9513</td>
<td>0.9400 to 0.9615</td>
<td>0.9512</td>
<td>0.9354 to 0.9649</td>
<td>0.9529</td>
<td>0.9350 to 0.9680</td>
</tr>
<tr>
<td>4 years</td>
<td>0.9618</td>
<td>0.9513 to 0.9710</td>
<td>0.9603</td>
<td>0.9456 to 0.9728</td>
<td>0.9643</td>
<td>0.9500 to 0.9763</td>
</tr>
<tr>
<td>5 years</td>
<td>0.9660</td>
<td>0.9535 to 0.9766</td>
<td>0.9637</td>
<td>0.9379 to 0.9828</td>
<td>0.9696</td>
<td>0.9522 to 0.9833</td>
</tr>
</tbody>
</table>
5-year completeness estimate
All cancer sites (but C44) by sex – All registries combined

![Graph showing completeness over time with different lines for both sexes, males, females, and lost cases.](image-url)
5-year completeness estimate
All cancer sites (but C44) – By registry

![Graph showing completeness over time since diagnosis for different registries: All registries, Ticino, Geneva, St. Gallen, and Lost. The x-axis represents time since diagnosis, and the y-axis represents completeness. The graph indicates that completeness increases over time and reaches a high level by 5 years.]
Percentiles of time (days) lagging between diagnosis and registration (1996-2000)

<table>
<thead>
<tr>
<th>Percentiles</th>
<th>TI+GE+SG</th>
<th>TI</th>
<th>GE</th>
<th>SG</th>
</tr>
</thead>
<tbody>
<tr>
<td>10%</td>
<td>4</td>
<td>2</td>
<td>27</td>
<td>5</td>
</tr>
<tr>
<td>25%</td>
<td>11</td>
<td>4</td>
<td>39</td>
<td>7</td>
</tr>
<tr>
<td>50%</td>
<td>39</td>
<td>9</td>
<td>63</td>
<td>13</td>
</tr>
<tr>
<td>75%</td>
<td>93</td>
<td>35</td>
<td>104</td>
<td>60</td>
</tr>
<tr>
<td>90%</td>
<td>418</td>
<td>1136</td>
<td>192</td>
<td>854</td>
</tr>
</tbody>
</table>
5-year completeness estimate
Respiratory system tumours (C30-C39) – By registry
5-year completeness estimate
Female tumours (C50-C58) – By registry

![Chart showing completeness over time by registry for female tumours (C50-C58). The x-axis represents time since diagnosis, ranging from 0 to 5 years. The y-axis represents completeness, ranging from 0 to 1. The chart includes lines for All registries, Ticino, Geneva, St. Gallen, and Lost. The completeness curve for Ticino shows the highest completeness, followed by All registries, Geneva, St. Gallen, and Lost.]
5-year completeness estimate
Male tumours (C60-C63) – By registry

![Graph showing completeness over time for male tumours (C60-C63) by registry.](image-url)
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)