SurvCan 3 Webinar on Data Quality: Trace back of DCO cases

International Agency for Research on Cancer
Lyon, France

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SURVCAN-3: Participating Registries

90 cancer registries from 36 countries
Active Follow-up & Trace back in SURVCAN-3

- Most data collections are done with much consultations & discussions
- 21 registries:
  - Follow-up of living cases
  - Trace back of DCO
  - Total population or a sample
  - Some with collaborative agreements
Active Follow-up & Trace back in SURVCAN-3

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Death certificate only (% DCO)

- The proportion of cancers for which no other information other than a death certificate mentioning cancer can be obtained
- Date of diagnosis = date of death = survival 0 days
- Measure of validity, since the information on death certificates well known to suffer from lack of accuracy, or lack of precision, compared with that obtained from clinical or pathology records.
- Acceptable level depends on local circumstances, availability of death certificates, success in record linkage, accuracy of cause of death in certificates
The process of using death certificates (DCs) to identify new cancer cases.
Survey 1

In your registry, do you routinely perform trace-back on DCO cases beyond routine matching to registry data?

1. Yes
2. No
3. Yes and no (for certain cases)
4. I don’t know
Improving validity and completeness: Trace-back of Death Certificates mentioning cancer

Look for clinical records via place of death – certifying doctor

What are the possible results?

Death Certificate

- No information on the patient
- Information on the patient

- No information about place of death in the certificate
- No information in the institution
- Institution closed
- Death at home; certifying doctor not identifiable/reachable

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Survey 2

In your registry, if you did not retrieve any additional information of the patient notified by Death Certificate, do you?

1. Keep the case as DCO
2. Keep the case as DCO only if the cancer is the underlying cause of death
3. Exclude the case
4. I don’t know
Improving validity and completeness: Trace-back of Death Certificates mentioning cancer

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**Death Certificate**

- No information on the patient
  - No information about place of death in the certificate
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- Information on the patient
  - Patient admitted to institution **BUT** clinical record does not exist
  - Patient admitted to institution **BUT** no permission to review clinical record
  - Patient admitted to institution **AND** clinical record exists and can be reviewed
Improving validity - Trace-back of DCO

- Patient admitted to institution **AND** clinical records reviewed

What are the possible situations you encounter?
How does the information change?

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### Improving validity - Trace-back of DCO

- **Patient admitted to institution** AND **clinical records reviewed**

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*International Agency for Research on Cancer*
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Survey 3

In your registry, if you retrieved additional information of the patient notified by Death Certificate, do you?

1. Change the basis of diagnosis
2. Verify the type of primary cancer
3. Change the date of diagnosis
4. All 1-3
5. Other, please fill in ...
6. Nothing, keep record as is
Improving validity - Trace-back of DCO

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<td>Decide Primary site, change base of diagnosis, assign incidence date, confirm address</td>
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Improving validity - Trace-back of DCO, example 1

A registry in Argentina, Incidence Cases diagnosed in 2006-2012

• 882 lung, stomach and liver cancer cases classified as DCO
• Trace-back in 2018 for survival study

<table>
<thead>
<tr>
<th>Cancer type</th>
<th>before trace-back</th>
<th>after trace-back</th>
</tr>
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<tbody>
<tr>
<td>Liver</td>
<td>31,8%</td>
<td>28,8%</td>
</tr>
<tr>
<td>Lung</td>
<td>21,2%</td>
<td>17,0%</td>
</tr>
<tr>
<td>Stomach</td>
<td>18,3%</td>
<td>13,9%</td>
</tr>
</tbody>
</table>

*17/173 (10%) had a different cancer
Survey 4

At your registry, when do you think trace-back of DCNs should be performed:

1. Immediately, when a DCN case appears
2. After data closing period e.g. around 1-2 years (or more)
3. For specific project e.g. cancer survival study
4. Never
Improving validity - Trace-back of DCO, example 2

A registry in Brazil, Incident Cases diagnosed in 2006-2012

- Total cases diagnosed in the period ~14000
- Trace-back in 2018 for survival study, all DCOs and a sample of breast cancer cases

<table>
<thead>
<tr>
<th></th>
<th>DCO before</th>
<th>DCO after</th>
<th>Total cases</th>
<th>Traced back</th>
<th>% traced back</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liver</td>
<td>83</td>
<td>52</td>
<td>168</td>
<td>31</td>
<td>37</td>
</tr>
<tr>
<td>Gallbladder</td>
<td>22</td>
<td>14</td>
<td>102</td>
<td>8</td>
<td>36</td>
</tr>
<tr>
<td>Pancreas</td>
<td>50</td>
<td>36</td>
<td>141</td>
<td>14</td>
<td>28</td>
</tr>
<tr>
<td>Lung</td>
<td>63</td>
<td>40</td>
<td>439</td>
<td>23</td>
<td>37</td>
</tr>
<tr>
<td>Prostate</td>
<td>55</td>
<td>48</td>
<td>1,624</td>
<td>7</td>
<td>13</td>
</tr>
<tr>
<td>Brain</td>
<td>42</td>
<td>21</td>
<td>172</td>
<td>21</td>
<td>50</td>
</tr>
<tr>
<td>Total</td>
<td>315</td>
<td>211</td>
<td>2,646</td>
<td>104</td>
<td>33</td>
</tr>
</tbody>
</table>
Impact on Survival estimate: Trace back of DCO, Brazil

• Survival estimates
  • Scenario 1 - Survival excluding all DCO
  • Scenario 2 - Survival using DCI (trace-back) and DCO excluded
Survey 5

What impact will trace-back of DCO cases on survival estimates in your registry

1. Increase the survival estimate
2. Decrease the survival estimate
3. Both
4. No impact
5. All above (1-4)
6. I don’t know
Acknowledgements

- Aude Bardot
- Adalberto Miranda
- Population-based Cancer Registry of Mendoza
- Population-based Cancer Registry of Aracaju