



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

International Agency for Research on Cancer
Lyon, France

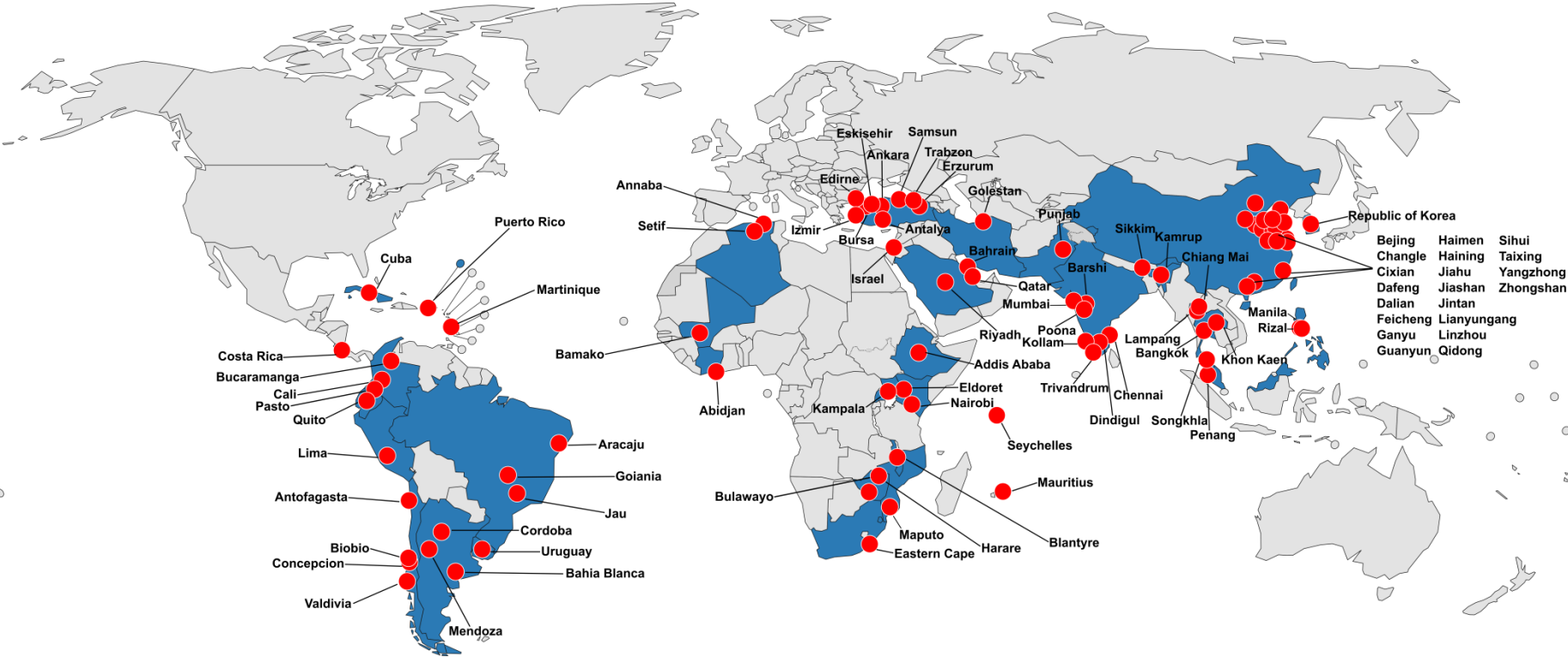
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SURVCAN Webinars
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SURVCAN-3: Participating Registries



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

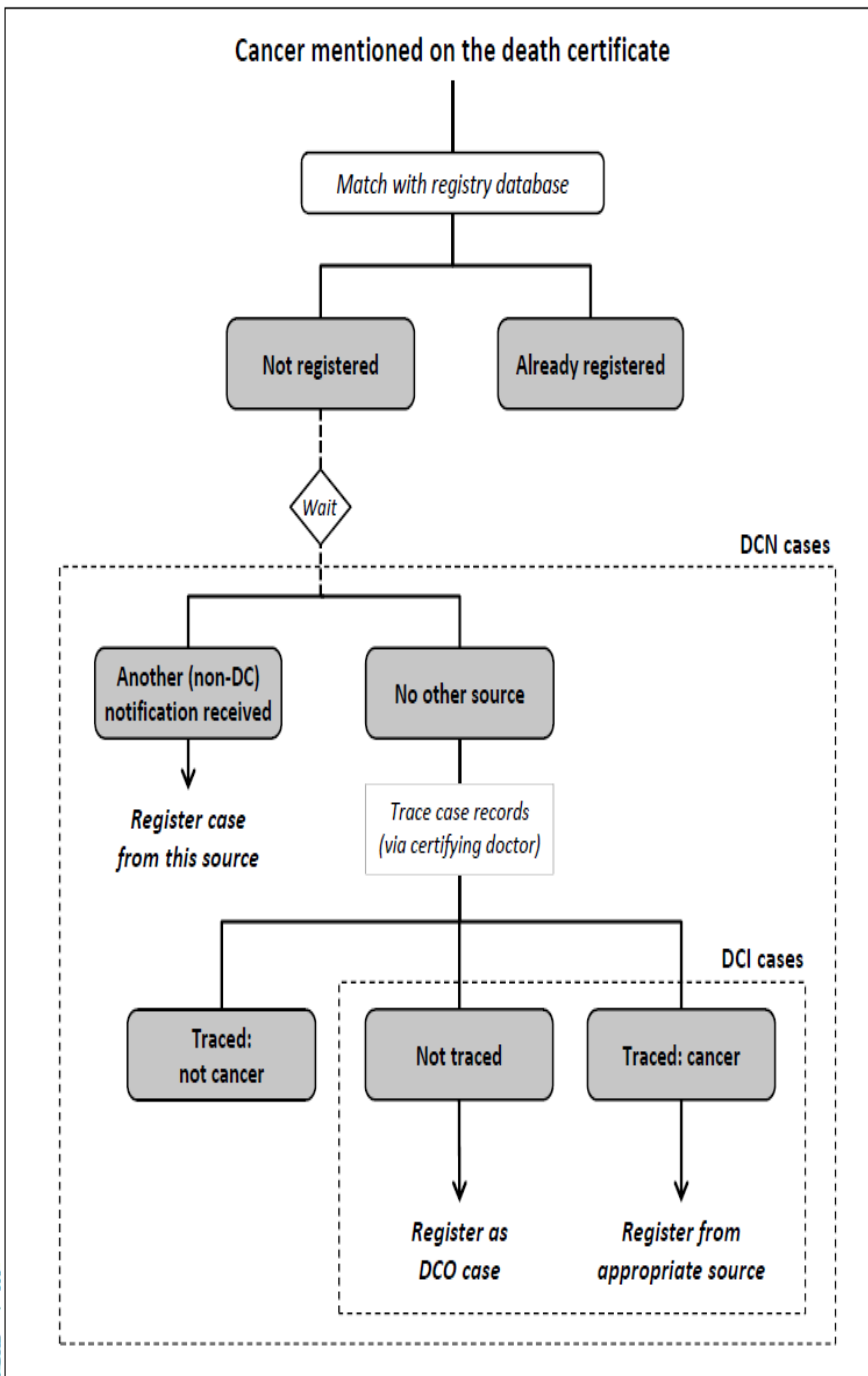
Active Follow-up & Trace back in SURVCAN-3

- 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

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

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graph TD; A[Death Certificate] --> B[No information on the patient]; A --> C[Information on the patient]
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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

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

Look for clinical records via place of death – certifying
doctor

What are the possible results?

Death Certificate

No 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

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?

Situation	Action
Medical record without cancer information	

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?

Situation	Action
Medical record without cancer information	Exclude the case from the registry

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?

Situation	Action
Medical record without cancer information	Exclude the case from the registry
Medical record with cancer information	

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

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

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

Situation	Action
Medical record without cancer information	Exclude the case from the registry
Medical record with cancer information - Cancer is the same in DC	

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?

Situation	Action
Medical record without cancer information	Exclude the case from the registry
Medical record with cancer information	
- Cancer is the same in DC	Change base of diagnosis, assign incidence date, confirm address
- Cancer differs to the DC	

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?

Situation	Action
Medical record without cancer information	Exclude the case from the registry
Medical record with cancer information	
- Cancer is the same in DC	Change base of diagnosis, assign incidence date, confirm address
- Cancer differs to the DC	Decide Primary site, change base of diagnosis, assign incidence date, confirm address

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

	Frequency	Percent
not found	599	67,9
patient admitted but there are no medical record in the clinic or hospital	84	9,5
death at home with medical record in clinic or hospital	7	,8
medical record where there is no cancer information	12	1,4
medical record with cancer information	173	19,6
medical record with information about another disease	7	,8
Total	882	100,0

Cancer cases diagnosed by death certificate

Cancer type	before trace-back	after trace-back
Liver	31,8%	28,8%
Lung	21,2%	17,0%
Stomach	18,3%	13,9%

***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

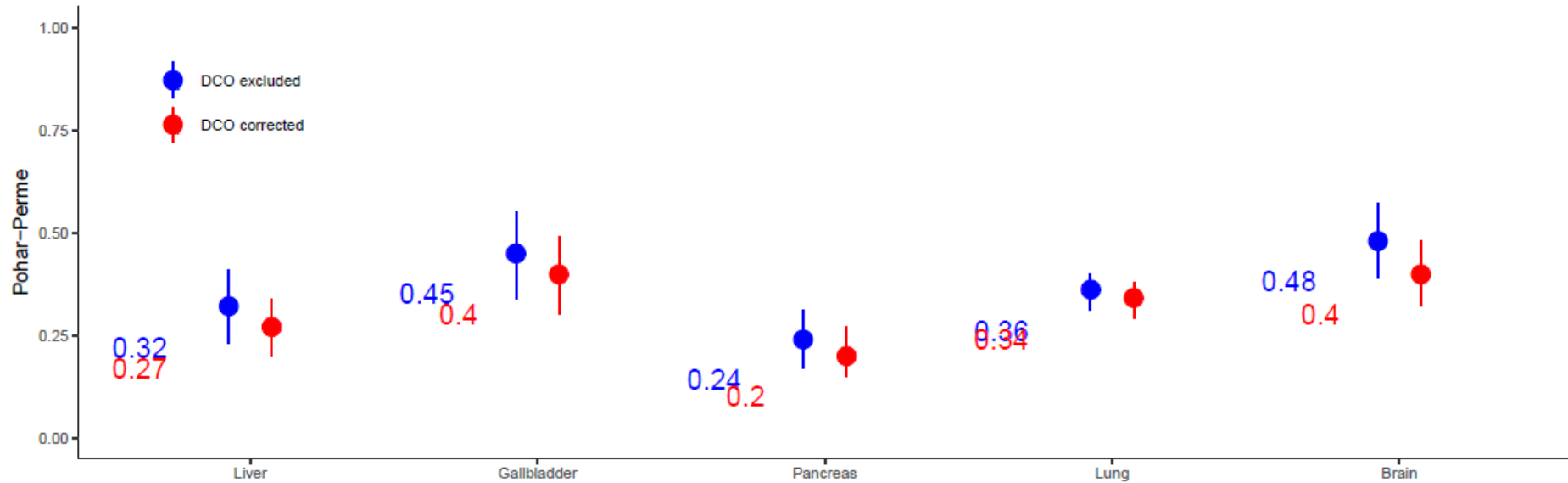
	DCO before		DCO after		Total cases	Traced back	% traced back
	N	%	N	%			
Liver	83	49	52	31	168	31	37
Gallbladder,	22	22	14	14	102	8	36
Pancreas	50	35	36	26	141	14	28
Lung	63	14	40	9	439	23	37
Prostate	55	3	48	3	1,624	7	13
Brain	42	24	21	12	172	21	50
Total	315	12	211	8	2,646	104	33

Impact on Survival estimate: Trace back of DCO, Brazil

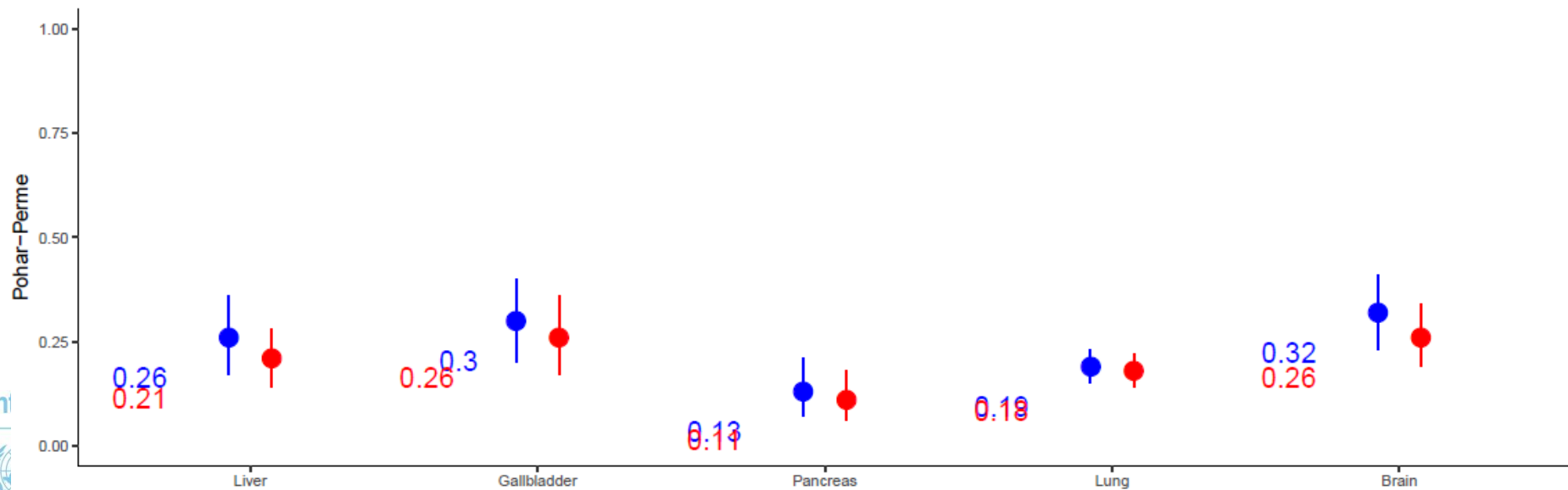
- Survival estimates
 - Scenario 1 - Survival excluding all DCO
 - Scenario 2 - Survival using DCI (trace-back) and DCO excluded

1-year survival

DCO = Death Certificate Only



3-years survival



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
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