DCN, DCI and DCO in the Cancer Registry of Norway

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Background:
Using death certificates (DCs) as a source of information is important to cancer registries as a means of ensuring completeness and evaluating validity. In this study, we wanted to follow the route of all the death certificate notifications from the linkage to the registry to ending up as a death certificate initiated (DCI) case or discarded as a new cancer case.

Method:
All deaths in Norway in the period 2011-2015 with cancer mentioned on the death certificate was linked to the cancer registry for matching. The notifications that were not matched (allowing for a 30 day wait) were labelled DCNs. The DCNs were divided into those that manually were considered not to be a new cancer case based on available information in the registry (e.g. the ICD-10 code of the death certificate corresponds to the location of a metastasis from a registered tumour) and those needing trace-back. The trace-back notifications were grouped into “traced not cancer” and “traced cancer”, the latter was labelled DCIs. The DCI cases were finally grouped into “traced with cancer confirmed from other source(s)” and “traced with no confirming source”, the latter labelled death certificate only (DCO) cases

Results:
From the total of 64308 death certificate notifications in the period 2011-2015, 87.4 % were already in the registry with a corresponding cancer. Of the remaining 8089 DCNs, 3105 were considered to not be a new cancer case based on manual evaluation within the registry and 247 based on trace-back, which combined constitutes 5.2 % of all death certificates and 41 % of the DCNs. There were 4737 DCIs, among which 1970 (41.6 % of the DCIs) ended up as DCOs.

Cancer mentioned on the death certificate (DC)
Cases based on DC during the period 2011-2015 (n = 64308)
Match with registry database

n = 56027

Already registered
Cancer case* that was already registered at time of match, automatic matching process of the two digit ICD10 code:

J:	Exact match	n = 46924
A:	Match on minor 1CD-10 group	n = 3198
B:	Match on larger 1CD-10 group	n = 5740

Cancer case that would be registered regardless of the DC, due to data from both the NPR and radiotherapy units. n = 165

Wait

n = 192

Another notification received
In principle, the CNR does not practice any wait before trace back. However, if another notification is registered within 30 days after the DC, we assume it was not traced back from the DC. It is more likely that it was traced due to other reminders, for instance based on data from the NPR.

DCN = 8089

To illustrate the process in detail the DCNs are grouped in different ways, but in principle they have two outcomes. One is being discarded as a new cancer case (red boxes), the other is ending up as a death certificate initiated (DCI) case in the registry (green boxes).

n = 3105

Manual evaluation at the CRN
The CRN contains information on cancer cases, premalignant cases and some benign tumors. Coders evaluate and conclude that the ICD10 codes from the DC do not belong to a new cancer case. They make their decisions based on in- house data, such as already registered cases, description in the DC and/or data from the NPR.

Benign case(s)
The DC was immediately registered as benign based on information from the death certificate alone, or in combination with other available sources. Note that the DC may contain information that do not correspond completely to the ICD-10-code on the DC.

The person is registered with:

- benign case(s) only	n = 834
- at least one cancer case	n = 126

Extension to already registered case(s)
One of the cancer specific causes of death mentioned on the DC provide no new information. It is assessed to be an extension to already registered case(s). For instance, the ICD-10 code corresponds to the location of the metastatic tumor, not the primary.

Manually evaluated DC, the person is registered with:

- benign case(s) only	n = 455
- at least one cancer case	n = 1528

The CRN have no image of the DC, the person is registered with:**

- benign case(s) only	n = 88
- at least one cancer case	n = 74

n = 4984

Not registered

DCI = 4737

Traced: Not cancer
Based on information from trace back to hospitals or other treatment facilities, the case was deregistered or ”coded down”:

The case was deregistered from the CRN, there was no cancer case	n = 154
The cancer case was “coded down” to pre-malignant.	n = 93
	n = 247

Traced (A): Cancer
The cancer case was registered from the appropriate source.

Same ICD10 code	n = 1023
Other ICD10 code	n = 49
No ICD10 code in the DC	n = 17
	n = 1089

Traced (B): Cancer
The cancer case was registered based on the DC and information from the NPR (available in-house).

Same ICD10 code	n = 1607
Other ICD10 code	n = 33
No ICD10 code in the DC	n = 38
	n = 1678

DC0 = 1970

Not successfully traced (DCO)
The cancer case was traced back*** to a hospital, treatment facility or a nursing home, but no information was returned. The CRN sends up to six reminders per case. The case was registered as a DCO.

n = 1970

*Types of diagnosis included in Cancer in Norway 2016 (https://www.kreftregisteret.no/en/General/Publications/Cancer-in-Norway/cancer-in-norway-2016) before counting multiple primaries. This also include some benign cases, for instance benign tumors of the central nervous system.
** Due to missing image of these DCs, the medical coder have no place to send reminders, and they made assessments based on available information
*** Trace back is not preformed if the death certificate provides information from a medical doctor in the primary care system only, and no hospital admissions in the Norwegian Patient Registry are available. As of 2014 this also applies to death certificates that provide information on nursing homes only.

Conclusion:
A large proportion (41 %) of the DCNs were judged to not be a new cancer case, indicating unreliability with death certificate information on cancers that are not already in the registry.

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