EUROPEAN JOURNAL OF CANCER 45 (2009) 756–764

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Review

Evaluation of data quality in the cancer registry: Principles and methods Part II. Completeness

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ARTICLE INFO

Article history:
Received 1 September 2008
Received in revised form
5 November 2008
Accepted 10 November 2008
Available online 6 January 2009

Keywords:
Cancer registry
Data quality
Completeness
Quality control

ABSTRACT

The completeness of cancer registry data – the extent to which all of the incident cancers occurring in the population are included in the registry database – is an extremely important attribute of a cancer registry. Only a high degree of completeness in case-finding procedures will ensure cancer incidence rates and survival proportions are close to their true value. This second instalment of a two-part review of data quality methods at the cancer registry, focuses on the principles and techniques available for estimating completeness, separating methods into those that are semi-quantitative – in that they give an indication of the degree of completeness relative to other registries or over time, and more quantitative techniques – those that provide a numerical evaluation of the extent to which all eligible cases have been registered.

1. Introduction

In Part I of this review, we considered the importance of comparability, validity and timeliness in the evaluation of cancer registry quality.[1] Here we review the evaluation of *completeness* – the extent to which all of the incident cancers occurring in the population are included in the registry database. Completeness is a very important attribute – only with maximum completeness in case-finding procedures will incidence rates and survival proportions be close to their true values. We present the principles and methods available for determining the extent to which this ideal is achieved.

These methods may be used to evaluate overall completeness of the registry database, or subsets within it, defined, for example, by type of cancer, area of residence, or age group. This is useful in identifying areas for improvement in registry procedures. Case-finding is often more problematical in the elderly, for example, since multiple pathologies may make hospital admission less likely, and extracting a cancer diagnosis from hospital information systems (or death certificates) less certain. The evaluation of completeness is important for all registries, but may be of special relevance to those making extensive use of automated data capture procedures, when case finding relies upon the accuracy (and complete-

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0959-8049/$ - see front matter
doi:10.1016/j.ejca.2008.11.033

ness) of other computerised databases, outside of the registries control.

It is useful to separate the methods for evaluation of completeness into two categories:

- *qualitative* (or *semi-quantitative*) methods that give an indication of the degree of completeness *relative to* other registries, or over time, and
- *quantitative* methods that provide a numerical evaluation of the extent to which all eligible cases have been registered.

2. Semi-quantitative methods

There are a number of methods that provide some indication of the completeness of a registry, but which do not actually quantify the number of cases missing (see 3). They include the following, discussed in more detail below:

1. Historic data methods:
   - Stability of incidence rates over time
   - Comparison of incidence rates in different populations
   - Shape of age-specific curves
   - Incidence rates of childhood cancers
2. Mortality:incidence ratios
3. Number of sources/notifications per case
4. Histological verification of diagnosis

2.1. Historic data methods

Most registries systematically review their data for unexpected or implausible trends in incidence, as a potential manifestation of changes in completeness of registration. The concept can be extended to include comparisons of results with those observed in other populations that might, *a priori*, have been expected to manifest similar rates. Both of these approaches have been widely used in the evaluation of datasets for *Cancer Incidence in Five Continents* (CI5).[2] Region-specific 'standards' were defined for the expected incidence rates of the major cancers (by sex), and the observed values compared with the standards. The assumption here is that the incidence rates for specific cancers will tend to be rather similar in datasets from the same region. The regional standards were derived as the mean and variance of values of the site-specific age-standardised incidence rates, and were calculated from the contributions to Volume VII of CI5.[3] Statistically significant differences in the observed values from those of the standard were flagged. Of course, differences from regional standards may reflect specific local variations in prevalence of risk factors, or the presence or intensity of screening for some cancers; nevertheless, systematic discrepancies (across several sites) provide evidence of possible under-registration (or over-registration, due, for example, to the inclusion of duplicate records).

With respect to childhood cancer, the incidence rates (for all types combined) in the childhood age groups (0–4, 5–9, and 10–14) show much less variability than in adults, although there are well-documented differences by geography or ethnicity for specific types of childhood cancer. The possibility of under-enumeration (or duplicate registrations) in this age range can be investigated by comparing the observed age-specific rates in the childhood age range with an 'expected' range of values. The limiting values for the lowest and highest deciles, published in Volume VIII of CI5[2] are shown in Table 1.

2.2. Mortality:incidence ratios

The mortality/incidence (M:I) ratio is an important indicator of completeness, an example of the 'independent case ascertainment method'.[4] It is a comparison of the number of deaths, obtained from a source independent of the registry (usually, the vital statistics system), and the number of new cases of a specific cancer registered, in the same period of time. When the quality of the mortality data is good (especially accurate recording of cause of death), and there is a steady state of constant incidence and survival, the M:I ratio is approximated by 1-survival probability (5 years) (Fig. 1).

Since both survival and the quality of mortality statistics are somewhat related to the level of socio-economic development,[5] the geographical region of the registry is important in evaluation of the statistic. In the evaluation of datasets for CI5[2], observed M:I ratios were compared with standard values from the same region, testing for significant differences, using the test described in the Appendix.

M:I values greater than expected lead to a suspicion of incompleteness (incident cancers missed by the registry), especially if it is so for several different sites. However, under- or over-reporting of tumours on the death certificates will distort the relationship, as will a lack of constancy in incidence and case fatality (the rate of death amongst incidence cases) over time. For example, when incidence is increasing while case fatality (or survival) is relatively constant, the M:I ratio will tend to be less than (1-survival), while conversely, if incidence is declining relative to case fatality, the M:I ratio will be greater than (1-survival), and may even exceed 1 for rather lethal cancers.

The M:I ratio has been used within the U.S. to provide a *quantitative* estimate of completeness of the different state registries.[6] A standard set of M:I ratios (site- and sex-specific, age-adjusted) from the SEER registries are applied to local mortality rates, and the expected incidence estimated, by sex and site. Completeness is evaluated as the observed/expected age-adjusted rates, allowing for the possibility that 20% of the difference (expected – observed) is due to differences in the M:I ratio between the locality tested, and the standard (SEER).

Table 1 – Values of incidence rates (per million) for upper and lower deciles of childhood cancer.[2]

Age	Boys		Girls	
	Lowest	Highest	Lowest	Highest
0–4	<12.3	>24.7	<9.7	>21.4
5–9	<8.5	>15.6	<6.9	>12.0
10–14	<8.5	>15.0	<6.8	>13.6

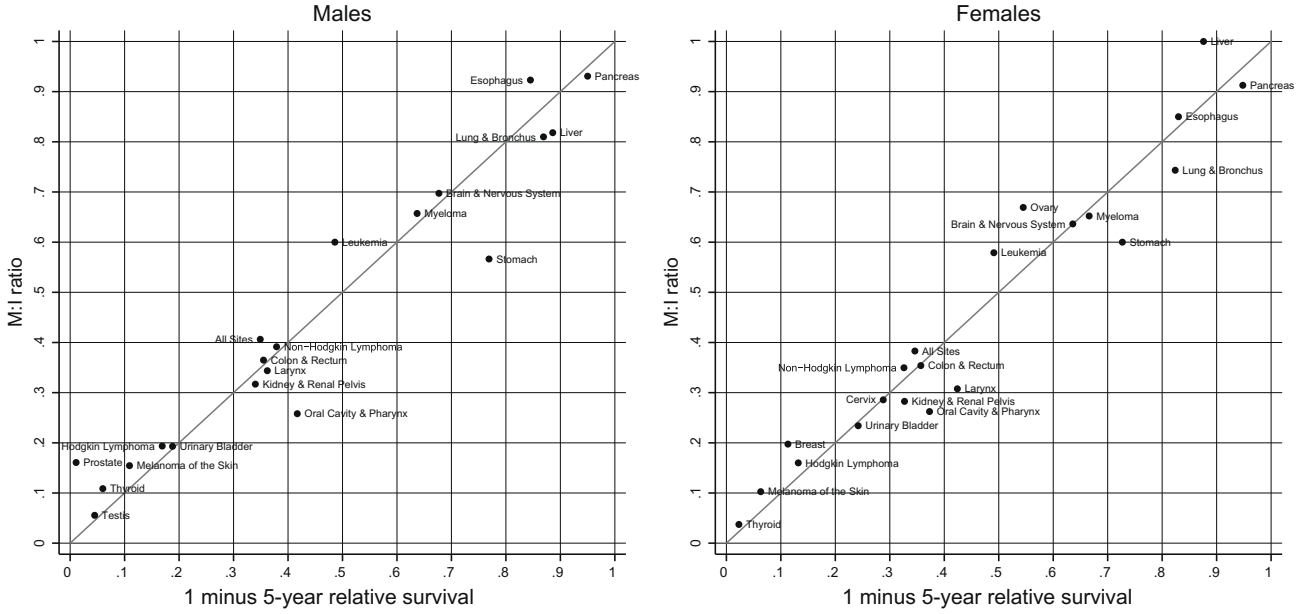


Fig. 1 – Mortality:incidence ratios (2001–2005) versus 1 minus 5-years relative survival (1996–2004). Statistics based on data from the SEER 9 registries (*Source*: SEER Cancer Statistics Review, 1975–2005[35]).

2.3. *Number of sources/notifications per case*

The rationale for using as many sources as possible is that it reduces the possibility of cancer diagnoses going unreported, thus increasing the completeness of the registry data. Two indices have been used as indirect indicators of completeness: the average number of sources per case, and the average number of notifications per case. Efficient record linkage is essential so that the same cancer case notified several times is recognised as such.[7] In considering notifications from within a single source, those arising from the same episode (hospital admission, pathological specimen) should not be identified as being separate notifications of the same case.

2.4. *Histological verification of diagnosis*

The main use of the indicator 'Percentage of cases morphologically verified' (MV%) is as a measure of validity, and methods for comparing of observed and 'expected' values of MV% are described in Part I. However, a very high proportion of cases diagnosed by histology or cytology/haematology – higher than might reasonably be expected – suggests over-reliance on the pathology laboratory as source of information, and failure to find cases diagnosed by other means.

3. Quantitative methods

Three methods are available to obtain a quantitative evaluation of the degree of completeness of registration:

1. Independent case ascertainment.
2. Capture–recapture methods.
3. Death certificate methods.
   - DCN/M:I method.[8]
   - The 'flow' method.[9]

3.1. *Independent case ascertainment*

Broadly speaking, there are two approaches to evaluation of completeness by this method:

- Re-screening the sources that had been used by the registry, to detect any case missed during the registration process.
- The use of one or more independent sources of cancer cases, and comparison of the registry database with them.

'Case-finding audits' are widely used in North America.[6] These involve independent reascertainment of records, usually in a sample of facilities and, within each facility, a sample of time periods. Records of cancer cases identified during the audit are enumerated and matched against the registry's files. Unmatched cases are followed back to verify their reportability, and the percentage of cases actually missed that should have been reported is calculated. Most such studies focus on hospital reporting and thus provide an estimate of the completeness of reporting for hospitals only, not a true estimate of completeness for a multi-source population-based registry. More realistically, this method has been used to evaluate completeness of case ascertainment by individual reporting facilities.

Comparison of the registry database with sets of cancer cases that have been compiled *independently* of the cancer registry's case-finding procedures is a particularly useful and objective method of evaluating completeness. It requires record linkage between the cancer registry database and the independent case series, to estimate the numbers of cases in the latter 'missed' by the registry. The proportion of eligible patients who are already registered is a direct and quantitative estimate of completeness. The method has been widely used, sometimes to investigate completeness of registration of all cancers, sometimes of a single type of cancer. Independent sources used for the purpose have included:

- Cases recruited into an international clinical follow-up study.[10]
- Patients enrolled into a multi-centre clinical trial.[11]
- The database of a registration network of family practices.[12]
- Cases identified in a cohort study.[13]
- Cases recruited into a multi-hospital case–control study.[14]
- Cases recorded in hospital databases not accessed by the registry.[15]
- Cases identified by a community survey.[16]

3.2. *Capture–recapture methods*

Capture–recapture was originally developed as a method of estimating the size of a closed animal population. The procedure is that at one time as many animals as possible in an area are captured, tagged and released – the 'capture' stage. At a later time this is repeated – the 'recapture' stage. The number of animals in each sample, and the number common to both, is used to estimate the number in the total population (assuming that capture and recapture are independent). Capture–recapture has been advocated for use in estimating completeness of disease registers,[17] and it has been applied several times to estimate the completeness of cancer registry data.[18–21]

Practically, capture–recapture analysis of completeness requires that record linkage is successfully carried out (so that cases identified by each of the multiple sources are correctly classified), and that, if death certificates are used as a source, the relevant cancer is correctly identified on them. In addition, two assumptions are made when using the simple capture–recapture method. The first is that when there are two sources, identification (capture) of a case by one of them is independent of the other, and, more generally, that there is no dependency between all sources in a multi-source model. The second is that all individuals have the same probability of being captured. Neither can be directly tested, and violation of either could lead to over- or under-estimation of the true patient population size.

It is likely that these assumptions will be violated in cancer registration. For example, in a cancer registry the sources commonly used are hospital discharge records, pathology reports, and death certificates. Cases captured by one source may be more, or less, likely to be also captured by the others, leading to dependence (positive or negative) between the sources and violating the first assumption. For example, terminally ill cases may be less likely than the average patient to be admitted to hospital (and thus not appear on a discharge record), and more likely to die (and to have cause of death recorded as cancer), so that there would be a negative dependence between these two sources. It is also possible that some subject characteristics would be associated with probability of capture (for example, subjects living near the border of the registration area may go to hospitals outside of it, and be missed by the hospital-based sources). These problems have led to distrust of capture–recapture as a method for estimating the completeness of registry data.[22] However, Brenner[23] using the Saarland cancer registry database, tested the interdependence of pairs of sources (clinical records, pathology, and death certificates), by evaluating the estimate of completeness for each pair, with respect to their known completeness in the third. An illustration of the estimation process is provided in Fig. 2. Although the two source capture–recapture estimates of completeness differed from the known values, the deviation was generally quite small, and was less severe than the bias made by assuming 100% completeness (no missed cases).

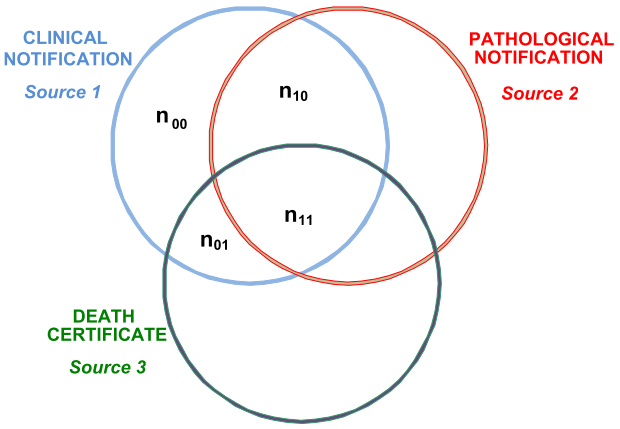
The problem of dependency between sources can be dealt with in several ways. Crocetti et al.[20] used Brenner's method to identify the degree of dependence between pairs of sources, then grouped those sources with the most dependence, before estimating the missing cases in a two way method with a third source. This method is applied by Larsen et al.[24] to the Cancer Registry of Norway data to estimate the completeness for each cancer site, given the estimated dependencies were mainly (weakly) positive between notifications by clinicians and death certificates, and from clinicians and pathologists, but negative between pathologists and death certificates. The dependence between the grouped sources and the third source was then calculated.

When the sources are all dependent, this approach cannot work, and log-linear modelling is needed. There are many possible models depending on the interactions included, for example, eight possible models with three sources), but the best approach is to use the model with all possible interactions.[25] Robles et al.[26] used data from three sources (clinical records, pathology records, death certificates) to estimate completeness of the cancer registry of Ontario, using two approaches. In one, a simple maximum-likelihood estimate was calculated from the three possible pairs of cases, and then all three data sources were used in a modelling approach. The latter was more flexible, since several variables that influence cancer registration can be considered and can be used to identify reporting patterns of different data sources, although the estimates of completeness of the registry as a whole were remarkably similar using either two or three data sources.

The log-linear modelling approach does not deal with the problem of the characteristics associated with capture, and an alternative is the inclusion of capture-related covariates in a logit model, which should improve accuracy of the estimate of the population size compared to estimates from a simple model.[27] In addition, this method can identify patient characteristics related to the probability of capture by different sources. Such information could be useful for the improvement of a recently-established registry by identifying patient subgroups with a high probability of being missed by the current registration procedures. The parameters from the model can also be used to estimate the number of cases in different population subgroups. For example, adjusted age- and sex-specific incidence rates can be derived.

3.3. *Death certificate methods*

Access to death certificates is important to cancer registries as a means of capturing information on cases that escaped the registration process during life. Fig. 3 illustrates the process of using death certificates mentioning cancer to make registrations of new cases. The use of statistics based on these 'death certificate cases' to evaluate quality of cancer registry data still apparently causes confusion, although this



		Source 3: Yes	Source 3: No
Source 2	Yes	n_{11}	n_{10}
Source 2	No	n_{01}	n_{00}

Total=n_{++}

$$\hat{n}_{00} = \frac{n_{10} \cdot n_{01}}{n_{11}}$$

$$\hat{n}_{++} = (n_{10} + n_{11}) \cdot \frac{(n_{01} + n_{11})}{n_{11}}$$

$$Comp_{known} = \frac{n_{11} + n_{10} + n_{01}}{n_{++}}$$

$$Comp_{estimated} = \frac{n_{11} + n_{10} + n_{01}}{\hat{n}_{++}}$$

Fig. 2 – Using capture–recapture methods to estimate completeness at the registry on the basis of three sources. In the example clinical notifications are considered as 'source one', with pathological notifications and death certificates, sources two and three, respectively.

has been clearly defined.[4,28] Completeness of registration may be evaluated on the basis of the proportion of incident cancers that come to the registry's attention via a death certificate mentioning cancer. A 'death certificate initiated' (DCI) registration is one for which the first information comes via a death certificate, and, without the death certificate, the case would not have been found. That is, any information from other sources (clinical or pathology, for example), was found *as a result* of trace-back procedures, *initiated* because of the death certificate.

Note that a DCI case is not the same thing as a case for which the information was received first via a death certificate notification (DCN), and for which subsequent information was received *without the need to establish a specific trace-back enquiry*. Depending on registry procedures, it is possible that information about a cancer death (from a death certificate) could be received before other relevant notifications (for example, a pathology report). It has been suggested that registries should identify a suitable interval between receipt of a DC notification, and initiation of a registration on the basis of this information. DCI registrations will also exclude cases notified via a death certificate which were subsequently found not to be cancers (Fig. 3).

DCO cases represent the residuum of cases – *after all trace-back manoeuvres have been completed on DCN cases* – for which no other information than a death certificate mentioning cancer could be obtained (Fig. 3). By itself, therefore, the DCO% is *not* an indicator of completeness of registration; a low DCO% may indicate efficient case-finding, but it could equally well result from the efficient trace-back of DCN cases. Nevertheless, the DCI% will always be equal to, or greater than, the DCO% (Table 2), so an elevated DCO% is suggestive of incompleteness.

Even the DCO% must be interpreted in the light of local circumstances. In some developing countries, the quality of death certificates may be very poor, with a fair number of deaths erroneously certified as cancer, which the registry may have difficulty tracing back to a hospital capable of confirming (or not) the death certificate statement.[29] The record linkage procedures of the cancer registry should also be capable of successfully identifying death certificate cases that are, or are not, already in the database.

Except for those DCO cases for which cancer was erroneously mentioned on the death certificate, DCI cases represent a failure to identify cases during life, and the proportion of such cases can therefore be used to provide a quantitative estimate of completeness. It should however be noted that the number of death certificate notifications will be high in the initial years of operation of a registry. This is because individuals dying with cancer at this time are unlikely to have been registered (since they would have been incident cases several years earlier). These deaths are unmatched, therefore, and, if the case cannot be traced, will also appear as DCOs.

Two methods of evaluating completeness based on death certificates are available, and can be used for all cases, or subsets defined by site or age group.

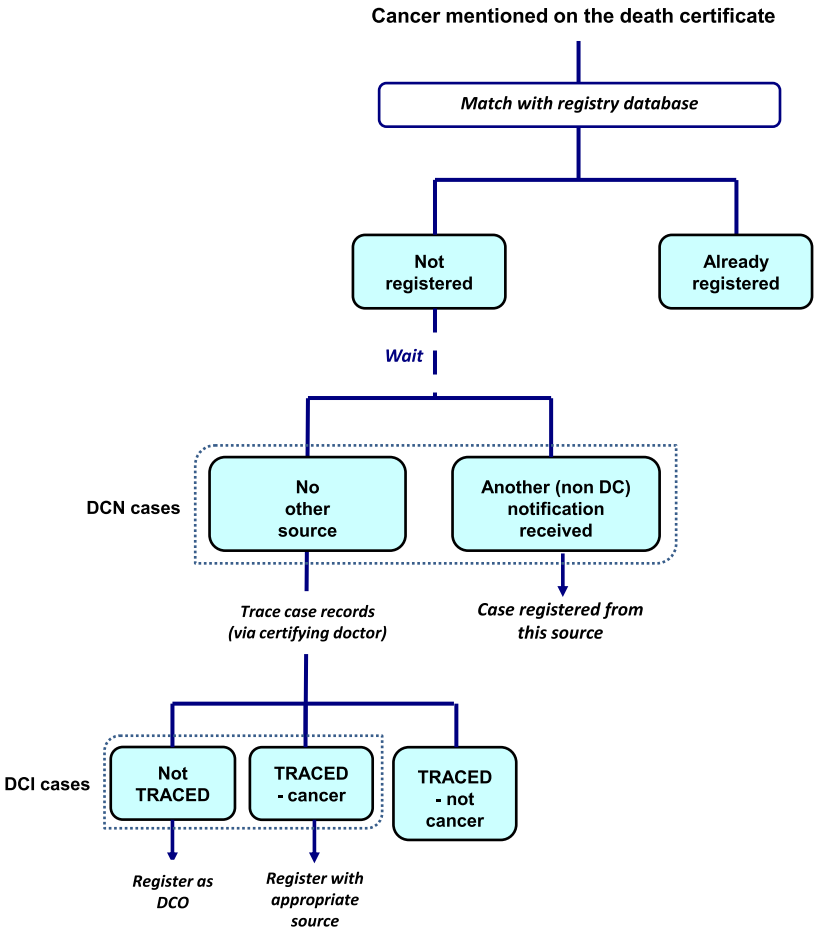


Fig. 3 – The use of death certificates to identify new cases of cancer.

3.3.1. *The DC and M:I method*[8]

The background to this method was described by Parkin et al.[4] It requires that death certificate initiated (DCI) cases can be explicitly identified by the registry, and makes use of the mortality:incidence ratio (M:I) to estimate the proportion of the initially unregistered cancer cases that do not die. The principle is illustrated in Fig. 4.

After inclusion of DCI cases (c) in the registry database, d represents the undetected cases presumed to be still alive, and the final degree of under-registration is given by $d/(a+b+c+d)$. In order to obtain a numerical estimate of d, it has to be assumed that the proportion of unregistered cancers that die $c/(c+d)$ is the same as the proportion of registered cases that die $a/(a+b)$.Thus, if $c/(c+d) = a/(a+b)$ then $d = bc/a$ or $(b/a) \times cd$ represents the undetected cases still alive, so the degree of completeness may be estimated as:

$$\frac{\textit{Final registrations}}{\textit{Final registrations} + d} \text{ or } \frac{a+b+c}{a+b+c+d}$$

Table 2 – Percentage of cases registered as DCN and DCO, and mortality:incidence ratios, in selected registries included in cancer incidence in five continents, Volume IX.[34]

Registry	DCN (%)	DCO (%)	M:I (all sites)	Completeness[a]
Brazil: Brasilia	60	4.3	33.5	–[b]
India, Mumbai	52	6.7	35.0	–[b]
Japan, Miyagi	14	12.0	48.6	82.8%
Korea, Daegon	33.1	4.1	50.1	50.7%
France, Somme	29	0.1	57.1	69.4%
Germany, Munster	18	9.3	52.9	80.4%
UK Thames	30	8.0	55.5	65.6%

a Calculated by Ajiki formula (Ref. [8]) and assuming DCN ≈ DCI.
b Cannot be calculated – combination of values of DCN and M:I are impossible.

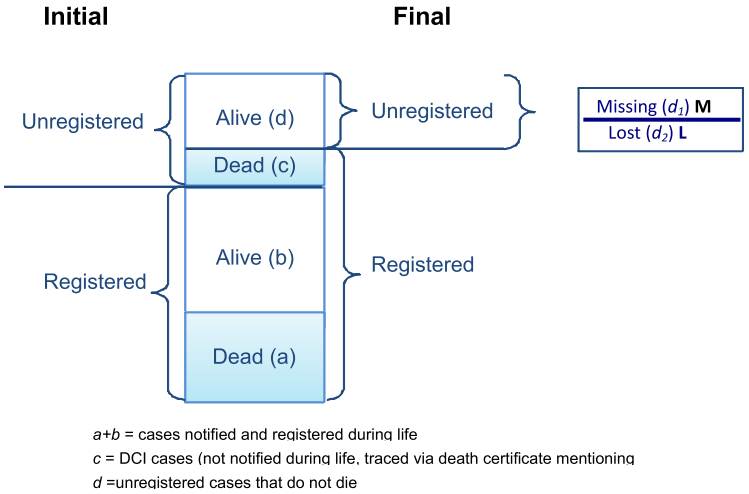


Fig. 4 – DCI as a measure of completeness (adapted from Parkin et al., 1994).[3]

The data required for the estimate are:

- The proportion of cases registered because of information from a death certificate ($c/a + b + c$).
- For the cases registered during life, the proportion that die (case fatality, or $a/a + b$).

For the latter quantity, one requires follow-up of the cases registered independently of a death certificate, to determine the proportion that die. An approximation to this case fatality is the mortality/incidence ratio (M:I) which is usually obtainable from death registration, independently of individual follow-up of registered cases. Although the M:I ratio includes DCI cases (in the nomenclature of Fig. 4, it is $(a + b)/(a + b + c)$), in practice this is not very different from the case fatality of non-death certificate cases ($a/(a + b)$), provided that the proportion of DCI cases is relatively small (say <10%).

Ajiki et al.[8] provide a formula for estimating completeness from DCI and the M:I ratio (both expressed as proportions)[e]:

$$\frac{1 - \mathrm{DCI} \times (1/\mathrm{M:I})}{1 - \mathrm{DCI}}$$

The method has been used to estimate completeness of registration in Japan.[8,30] The assumption behind the estimate is that the case fatality is the same for registered and unregistered cases. This is probably untrue, since other studies suggest that such cases are likely to be older, less investigated and less intensively treated – and hence with higher fatality – than the cases detected by the usual case-finding procedures of the registry. An additional assumption is that M:I ratios (related to survival) are relatively constant over the short time periods being considered.

3.3.2. *The Flow method*[9]

This method estimates the cases not traced via death certificates using information on survival of registered cases, and, based on cancer patients that have died, the probability of registration at different intervals post-diagnosis. It does not, therefore, require that DCI cases are explicitly enumerated, and is not sensitive to the proportion of DCIs, or to the assumption of equal M:I ratios in cases that are, or are not, traced.

Referring to Fig. 4, it can be seen that d, the cases remaining unregistered even after inclusion of DCI cases, includes two components:

- d_1 – missing cases – unregistered cases that did not die (M)
- d_2 – lost cases – unregistered cases that died, but for whom cancer was *not* mentioned on the death certificate (L).

To estimate these two fractions, three parameters must be derived:

(i) The probability of surviving different intervals after diagnosis ($s(t_i)$). This is derived by a conventional survival analysis (actuarial method), but the DCO cases should not be excluded, since, if they are numerous, the survival probability will be too great. But, DCO cases are conventionally assigned a date of diagnosis equal to the date of death (i.e. a survival time of zero). To avoid this, DCO cases are taken as incident in the year they occur (the conventional assumption), but, their survival is imputed from that of the DCN cases registered in the same year.

(ii) The probability that cancer is not mentioned on the death certificate, at different intervals post-diagnosis $1 - m(t)$. $m(t)$ is obtained for the cancer patients who died in the survival analysis.

(iii) The probability that a patient *that died* had not been registered at different intervals post-diagnosis $u(t_i)$.This is calculated based on the cancer patients who died, as 1 – (probability of registration at time t_i post-diagnosis). Bullard et al.[9] suggest omitting the year before death, when calculating $u(t_i)$.

[e] The formula provided on page 19 in the original publication by Parkin et al.[4] is in error.

Missing cases (M) are given by $s(t_i) \times u(t_i)$.

Note that, here, $u(t_i)$ should be the probability that a patient *that had not died* had not been registered at different intervals post-diagnosis. Clearly, Bullard et al. assume that this would be well approximated by the statistic calculated in (iii), based on dead patients only.

Lost cases (L) are given by $[s(t_i) - s(t_{i+1})] \times [1 - m(t_i)\ ] \times [u(t_i)]$

N years after diagnosis, the lost cases would be:

$$\sum_{i=0}^{n} [s(t_i) - s(t_{i+1})] \times [1 - m(t_i)] \times [u(t_i)]$$

Completeness at time T ($C(T)$) is given by $1 - M(T) - L(T)$.

A computer programme is available for carrying out the necessary computations.[31] Montanaro et al.[32] describe a modification to the basic method, for cancer registries where the routine procedures include a delay (of a year or two) between the incidence date, and registration. The method has been used to examine the effect of incomplete registration on estimates of survival in Thames Cancer Registry (United Kingdom) and Finland,[33] and is applied to assess the completeness of registration in 1999 in the Cancer Registry of Norway.[24] The flow method provides estimates of completeness of registration in a given year at successive time intervals following the end of that year (see Fig. 5 of Ref. [24]), and therefore provides information on the timeliness of registration procedures.

Conflict of interest statement

None declared.

Acknowledgements

This study was undertaken as part of the Cancer Control using Population-based Registries and Biobanks (CCPRB) project, funded by the EU Sixth Framework Programme (FP6-2002-LifeSciHealth Contract No. 503465).

Appendix. Statistical Test for comparison of the Registry M:I ratio, by site, with standard values.[e]

The comparison populations are registries in the same country, or region indexed by $i = 1, \ldots, n$.

d_i = number of cases in registry i
m_i = number of deaths in registry i

We start with a *Poisson* model for m_i/d_i in which the ratio of expected values is θ. This model can be converted to a binomial model by conditioning on the total number of cases and deaths $n_i = m_i + d_i$.

Then,

$$\theta = \frac{\sum_{i=1}^{n} m_i}{\sum_{i=1}^{n} d_i}$$

Define

$$\hat{\phi} = \frac{1}{n-1} \sum_{i=1}^{n} \frac{(m_i - \hat{\theta} d_i)^2}{n_i \hat{\theta}}$$

For the Registry under test, with cases d_j and deaths m_j, the test statistic is

$$Z^2 = \frac{(m_j - \hat{\theta} d_j)}{\hat{\phi} n_j \hat{\theta}} \sim \chi_1^2$$

So the Registry is flagged as unusual if $Z^2 \geqslant 3.84$.

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