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Completeness and timeliness: Cancer registries could/should improve their performance

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KEYWORDS
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Abstract Cancer registries must provide complete and reliable incidence information with the shortest possible delay for use in studies such as comparability, clustering, cancer in the elderly and adequacy of cancer surveillance. Methods of varying complexity are available to registries for monitoring completeness and timeliness. We wished to know which methods are currently in use among cancer registries, and to compare the results of our findings to those of a survey carried out in 2006.

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Methods: In the framework of the EUROCOURSE project, and to prepare cancer registries for participation in the ERA-net scheme, we launched a survey on the methods used to assess completeness, and also on the timeliness and methods of dissemination of results by registries. We sent the questionnaire to all general registries (GCRs) and specialised registries (SCRs) active in Europe and within the European Network of Cancer Registries (ENCR).

Results: With a response rate of 66% among GCRs and 59% among SCRs, we obtained data for analysis from 116 registries with a population coverage of ~280 million. The most common methods used were comparison of trends (79%) and mortality/incidence ratios (more than 60%). More complex methods were used less commonly: capture–recapture by 30%, flow method by 18% and death certificate notification (DCN) methods with the Ajiki formula by 9%.

The median latency for completion of ascertainment of incidence was 18 months. Additional time required for dissemination was of the order of 3–6 months, depending on the method: print or electronic. One fifth (21%) did not publish results for their own registry but only as a contribution to larger national or international data repositories and publications; this introduced a further delay in the availability of data.

Conclusions: Cancer registries should improve the practice of measuring their completeness regularly and should move from traditional to more quantitative methods. This could also have implications in the timeliness of data publication.

1. Introduction

The main goal of a population-based cancer registry is to continually collect data on all cancer cases occurring in the population resident in a defined area and to use the incidence data to provide information on risk. Incomplete ascertainment of cases greatly limits the value of the data, regardless of the amount of data collected on each case. Completeness of ascertainment – the extent to which all incident cases targeted by the registry (including subsequent cancers) are identified and included in registration – therefore remains the principal test of a cancer registry; beside accuracy in recording, classification and coding of diagnosis, complete ascertainment is crucial for providing accurate incidence rates, unbiased survival, and other statistics. Nowadays, when data collection is for many registries supported by the availability of a wide range of different sources, this task should be relatively easy. However, only thorough and painstaking monitoring, with precise and specific methodology, can provide assurance with documentation that this goal has been achieved. Incompleteness in case identification may not be uniform or consistent: for example, case finding is often more difficult in the very elderly, where multiple pathologies can make extracting information on cancer diagnosis from hospital records or death certificates more problematic [1]. Organisation of the health-care system can also affect the probability of a certain type of tumour being reported, resulting in variation in completeness of registration by cancer site. It is worth considering that incompleteness in case ascertainment may not only bias the incidence statistics, it will also affect survival and prevalence data, since not-ascertained cases are most probably not random but associated with a different probability of surviving when compared to ascertained cases [2]. The bias is even larger when associated with incomplete follow-up [3].

Several methods for assessing the completeness of registration have therefore been devised to detect whether, and how, cases may be missed; each of these methods addresses a particular aspect of the problem. Reviews of these methods can be found in Parkin and Bray [4,5] and Schmidtmann and Blettner [6], and are briefly summarised here.

Qualitative or semi-quantitative methods suggest a lack of completeness, compared to other registries, or over time, but do not actually quantify the number of missing cases. These are:

1. historic data/comparative methods [7]
   a. stability of incidence rates over time;
   b. comparison of incidence rates in different populations;
   c. shape of age-specific curves;
   d. incidence rates e.g. of childhood cancers.

2. mortality: incidence ratios [7]; log-linear variant [8]
3. number of sources/notifications per case [7]
4. microscopic verification of diagnosis [7].

Quantitative methods provide a numerical evaluation of the extent to which all eligible cases have been registered. These are:

1. independent case ascertainment [7];
2. capture–recapture methods [10–12];
3. death certificate methods:
   a. death certificate notification (DCN)/mortality:incidence (M:I) method [7,13];
   b. flow method [14–16].

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Moreover, it can be mentioned that the MIAMOD/PIAMOD modelling methods [9] have also been used as possible tools for indirectly estimating completeness on the grounds of the comparison between observed and modelled numbers of cases.

Timeliness in the publishing of results can be related to completeness: registries may have a tendency to delay the dissemination of their results in order to achieve better completeness, so that there can be competition between the two goals. Availability of quantitative methods that allow estimation of completeness at a given stage of the registration process could help registries to decide in a more rational way when data can be considered ready for publication. Although studies on the completeness of registration in single cancer registries or networks of registries have been published in peer-reviewed journals [17–31], no overview of the situation in Europe was available prior to the survey of registries in 2006 [6]. This survey asked registries, both general and specialised, about the methods they used to estimate completeness. With a response rate of 29%, the survey showed that the majority of cancer registries used qualitative methods, with only a minority (about 20%) using quantitative methods such as capture–recapture or flow methods; few had made comparisons between methods. Evaluations of timeliness are rarely published in peer-reviewed journals [29,32,33].

Therefore, in the framework of the EUROCOURSE project (http://www.eurocourse.org) we decided to repeat the survey while attempting to improve the response rate and adding questions about the data available on different methods for the estimation of completeness. We also added a section on timeliness of publication of results, which relates to completeness.

2. Materials and methods

The target population was all registries in the network of population-based cancer registries active in Europe, both general (GCR) or specialised (SCR). Based on the 206 registries currently on the European Network of Cancer Registries (ENCR: http://www.encr.eu/) member list, 179 were identified as currently active, having recently provided data; these registries, from 32 European countries, formed the target population. SCRs included in the survey were those collecting information only on patients of a defined age (childhood) or on cancer of a specific site or tract (for example, of the digestive or haematopoietic system, mesothelioma, breast cancer).

The questionnaire of the previous survey [6] was updated and structured in four sections. The first section contained questions on the type of activity (specialised or general) of the registry, its institutional setting, the population size covered and its period of operation. The second section explored the availability, and the current method of collection, of information required to estimate completeness using different methods. The third section asked for information on the methods, if any, used by the registry to assess completeness, how and when the estimation was performed, and where the results were published – or the reasons for not performing an estimation. Registries were also asked to provide a self-assessed estimate of their completeness and to provide information on the availability of software, comparisons of the performance of different methods, references, contact details and interest in feedback. The last section asked about the timeliness of data publication under different circumstances.

We first sent an invitation letter to the 179 registries. The questionnaire was then posted on the ENCR website in January 2011 and a reminder was sent at the end of February. The returned questionnaires were uploaded to a MySQL database [34], and then exported for analysis in SAS 9.2 format [35]. We computed relative and absolute frequencies, presenting the results in tables and graphs. Registries were grouped by country and into four regions within Europe, as defined by the United Nations Population Division [36].

3. Results

Of the 179 European cancer registries (24 specialised) contacted, 116 (65%) replied: 102 GCR (a response rate of 66%) and 14 SCR (a response rate of 59%). The population covered by the responding registries was more than 280 million, corresponding to about 50% of the population of the 32 countries where registries were invited to participate. Table 1 shows the respondent registries by country and region. The majority of respondent registries (62%) began activity after 1980; 41% covered a population of 1 million or fewer inhabitants (Table 2).

3.1. Completeness

Of the respondent registries, 88% stated that they checked completeness in some way: 86% of GCRs and 100% of SCRs (Table 3). The reasons advanced by the 14 registries (all general) that did not estimate completeness were: lack of time, software or trained staff, and, in two cases, the belief that this estimate was not necessary.

The most common method used was historical comparison of rates with previous years (79%), followed by methods based on the mortality/incidence ratio (more than 60%) (Table 4). Slightly fewer registries (30%) used methods based on death certificate notification (DCN), including those based on the formula proposed by Ajiki. The capture–recapture method was used by 30% of registries, the flow method by 18% and the

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Table 1
Respondent population-based cancer registries by country and population coverage by European region (according to the United Nations Population Division).

Country	Respondents	Covered population
Denmark	1	
Estonia	1	
Faroe Islands	1	
Finland	1	
Iceland	1	
Ireland	1	
Lithuania	1	
Norway	1	
Sweden	2	
UK	9	
Subtotal North	19	79,423,768
Austria	2	
Belgium	1	
France	20	
Germany	10	
Switzerland	10	
The Netherlands	2	
Subtotal West	45	103,954,016
Belarus	1	
Bulgaria	1	
Czech Republic	1	
Hungary	1	
Poland	7	
Romania	2	
Slovakia	1	
Subtotal East	14	55,672,762
Croatia	1	
Italy	21	
Malta	1	
Portugal	3	
Serbia	1	
Slovenia	1	
Spain	10	
Subtotal South	38	4,445,0723
Total	116	283,501,269

Table 2
Number of respondent general cancer registries (GCRs) and specialised cancer registries (SCRs) in Europe by length of activity and population covered.

Year of starting activity	GCRs	SCRs	Total
Old (year start $\leqslant$1980)	36	8	44
Intermediate (1980 $<$ year start $\leqslant$ 2000)	54	5	59
New (year start >2000)	12	1	13
Population covered			
Large (>2 million)	39	4	43
Medium (1 million $<$ population covered $\leqslant$2 million)	20	5	25
Small ($\leqslant$1 million)	43	5	48

MIAMOD/PIAMOD by only 14% (Table 4). As a whole, 53% of the registries used at least one quantitative method. The use of quantitative methods seemed to be independent of the size of the registry, being equally often used by large and small registries, but less often used by middle-size registries (data not shown).

Table 3
Practices of measuring completeness in general and specialised European cancer registries (CR).

	Yes	%	No	%	Total
General CR	88	86	14	14	102
Specialised CR	14	100	0	0	14
Total	102	88	14	12	116

Regional differences in the methods used were small, but quantitative methods were used more frequently by Northern registries, with the exception of the MIAMOD/PIAMOD method which, although not commonly used, was more often used by registries in Southern Europe (Fig. 1). The flow method was used by only 18% of registries.

As one of the possible barriers to estimating completeness was the lack of specific software, we also asked about the availability and use of software (Table 4). More complex computational methods were usually carried out with dedicated software, while the users of simpler methods less frequently reported the availability of dedicated software.

In general, completeness estimates were most often performed by epidemiologists and statisticians, while computer scientists, physicians, registrars and external researchers were far less likely to do so (Table 5).

Among registries which estimated completeness, only 21% said they had published the results in a peer-reviewed journal, while the majority (40%) used internal technical reports. However, many had not published the results anywhere (36%).

A separate question asked about self-assessment of completeness. For registries which said that they measured completeness, the answer was presumably based on the results of this measurement (Table 6); those which stated that they did not routinely measure completeness did not answer this question, except for two which – in evident contradiction – declared their completeness to be over 90%.

3.2. Timeliness

The median time to completion of the last year of incidence was 18 months, with wide variations (mean: 21 months; range: 4–60 months) (Table 7).

After the completion of case ascertainment, the delay in publishing the data varied according to the method of publication. Preparing and publishing a printed report appeared to take an average of 7 months (range: 1–42 months). This time was shorter (3 months on average; range: 1–30 months) if data were published on the registry website. The time taken to send data to national or international databases was similar (4 months on average; range: 1–18 months).

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Table 4
Frequencies of use of different methods by general cancer registries (GCRs) and specialised cancer registries (SCRs); total number of registries (GCRs + SCRs) = 102. Multiple answers on methods were allowed.

Method	GCRs	SCRs	% of total number of registries (102)
Historical comparison [7]	68 (37)	13 (3)	79
Compare incidence with incidence in reference registry [7]	54 (35)	9 (3)	62
Comparison with reference registry (indirect standardisation) [7]	31 (16)	3 (2)	33
Death certificate notification (DCN) method [7]	31 (18)	1 (1)	31
DCN method (Ajiki's formula) [13]	9 (7)	0 (0)	9
M/I ratio: compute and compare with other registries/national average [7]	62 (34)	2 (2)	63
M/I ratio: compute and compare with own registry in previous year(s) [7]	68 (47)	3 (3)	70
Log-linear models [8]	11 (5)	0 (0)	11
Independent case ascertainment [7]	30 (15)	4 (1)	33
Flow method (Bullard) [14–16]	17 (12)	1 (1)	18
MIAMOD/PIAMOD [9]	14 (11)	0 (0)	14
Capture recapture [10–12]	27 (15)	4 (1)	30
Other	10 (6)	3 (1)	13

In parentheses: number of registries that reported the availability of dedicated software for that method. M/I ratio, mortality/incidence ratio.

Only a very small number of registries (3) did not answer any of the questions related to timeliness in completing incidence and publishing results.

4. Discussion

The proportion of respondents to the present survey was higher than that to the previous one (65% versus 29%). The response rate was similar in different European regions and for general and specialised cancer registries; respondents were representative of different extents of population coverage and length of operation.

The proportion of responding registries which stated that they evaluated completeness was similar in the present survey (88%) to that in the previous one [6] conducted in 2006 (86%). The methods used for estimating completeness were still largely based on simple compar-

Table 5
Professionals who perform completeness estimates in European cancer registries (more than one answer possible).

Professionals	Registries
Epidemiologist	63
Statistician	42
Computer scientist	19
Physician	19
Registrar/documentalist	14
External researcher	16

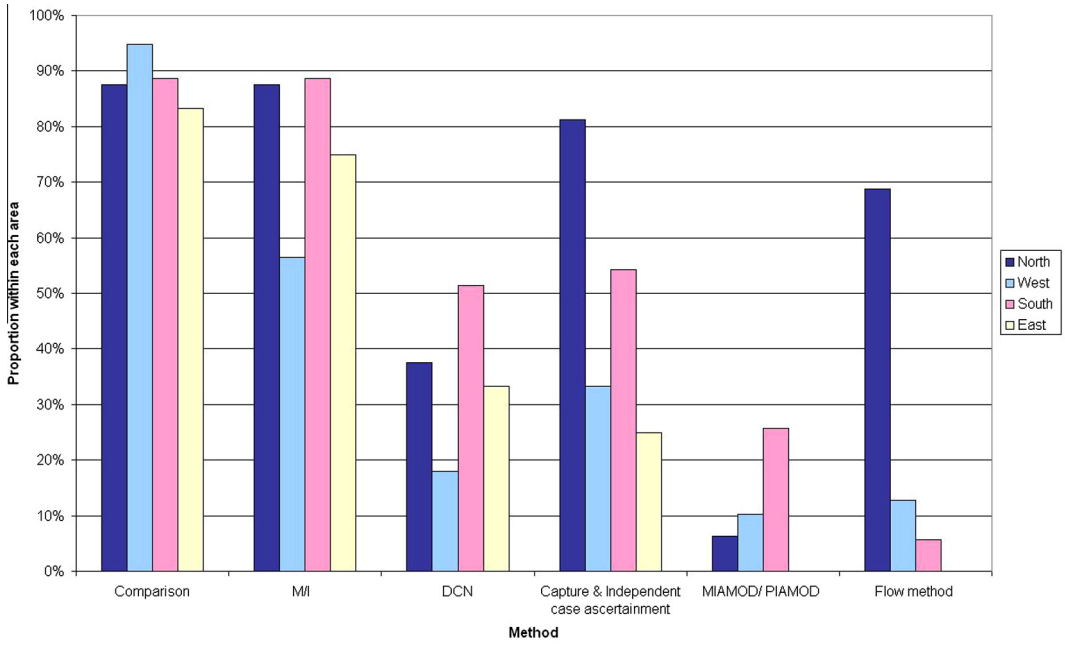

Fig. 1. Use of main methods for estimating completeness. European cancer registry by region (countries grouped according to the definition of the United Nations Population Division).

Table 6
Number of European cancer registries according to self-assessed percentage of completeness.

Percentage of completeness	Registries		
	GCR	SCR	Total
No answer	1	0	1
<50%	0	0	0
50% to <60%	0	0	0
60% to <70%	0	0	0
70% to <80%	2	0	2
80% to <90%	7	1	8
90% to <95%	25	2	27
≥95%	53	11	64

GCR, general cancer registry; SCR, specialised cancer registry.

Table 7
Latency for completing 1 year of case ascertainment and releasing data of European cancer registries (in months).

	n	Mean	Median	Minimum	Maximum
Complete 1 year of incidence	113	21	18	4	60
Publish printed report	92	7	6	1	42
Publish data on internet	89	6	3	1	30
Forward data to national or international databases	107	4	4	1	18

isons with previous data from the registry, or with that of other registries. Quantitative methods had increased slightly in use since the 2006 survey, but had not yet become the methods of choice. With respect to different methods available, a 'country' effect was recognisable for the flow method [14–16], which was mainly used in Northern countries, whereas the MIAMOD/PIAMOD method [9] was used mainly in Southern countries, corresponding to the regions where the two methods were first devised and used. It can be observed that MIAMOD/PIAMOD modelling methods allow only an indirect estimate of completeness.

The self-assessment of completeness was optimistic and was probably overestimated by registries which claimed to reach a high level of completeness but did not use quantitative methods to estimate it. Estimates of completeness – as assessed by cancer registries which used quantitative methods – were more reliable.

It is well known that the performance of cancer registries in achieving completeness is dependent on factors such as cancer site, age of subject, length of survival, frequency of relapses, etc. Also some of the methods for assessing completeness can be conditioned by the above factors: an example is the case of the capture–recapture method, whose precision could depend on the number of sources – and therefore by the diagnostic pressure – depending on patient age and cancer type. Methods based on DCN required the availability of death certificates and recording on how they were processed, and that it is not always the case. The practice of the flow method is influenced by the choice of the date of registration, which depends on the setting and procedures of registration. Even with these challenges, quantitative methods seem to be preferable because they enhance attention and work on the problem of completeness. Considering that different quantitative methods were introduced between 1994 and 2000, and that they require minimal expertise to be performed, one could have expected that they might have reached a larger dissemination, but the survey showed that just 53% of registries declared the use of at least one of them.

The answers to the question about the availability of dedicated software to perform methods for estimating completeness were probably affected by misunderstanding: for more sophisticated methods, such as the flow method, refined computational activities are necessary, but probably not all the users regarded them as 'dedicated software'. The availability of standardised tools could probably be welcome.

The survey showed a median delay of 18 months in publishing data, which can be considered acceptable. The range was quite large. Some registries were fast (with data complete 4 months after the end of the relevant year), while others took up to 5 years; the latter were probably registries that performed registration in 3- or even 5-year batches. For the registries (still a majority) which produced a printed report, this took on average 6 months; publishing data on the registry website took less time (3 months), but this method of dissemination did not seem to have replaced printing, and the two seemed to continue in parallel. Almost all registries sent their data to national or international databases, with a short delay. We did not observe any significant association between the use of quantitative methods in assessing completeness and any gain in timeliness in producing and publishing the data.

Timeliness is related to completeness in a complex way. Registries tend to delay publication of results, waiting to achieve better completeness. However, if registries estimate completeness only with qualitative methods, it is difficult to have a rational trade-off between completeness and timeliness. Only the flow method allows registries to measure completeness during the registration process and therefore to decide the level of completeness at which to publish the data.

Unlike the US SEER registries, for which the whole process of registration (type of data, their qualities and the latency in production) is a matter of a contract with the funding bodies, for European registries there are no standards to comply with.

The international registry groups – such as ENCR and IACR, as well as research consortia which use registry data – should encourage cancer registries to

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estimate their completeness with quantitative methods through recommendations and support for the standardisation of methods.

Timeliness in data production and publication should also benefit from the use of quantitative methods for assessing completeness.

Conflict of interest statement

None declared.

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