Estimating Completeness and Timeliness in Cancer Registries in Europe: a Survey promoted by the EUROCOURSE Project

R Zanetti[1,*], I Schmidtmann[2], S Rosso[1], L Sacchetto[1], F Binder-Foucard[3], A Bordoni[4], D Coza[5], S Ferretti[6], J Galceran[7], A Gavin[8], N Larranaga[9], D Robinson[10], L Tryggvadottir[11], E Van Eycken[12], V Zadnik[13] and JWW Coebergh[14]

[1]Piedmont Cancer Registry, CPO, Turin, Italy.

[2]Institute of Medical Biostatistics, Epidemiology and Informatics, University of Mainz, Mainz, Germany.

[3]Registre des Cancers du Bas-Rhin, Strasbourg, France.

[4]Ticino Cancer Registry, Locarno, Switzerland.

[5]Cluj Regional Cancer Registry, Cluj-Napoca, Romania.

[6]Ferrara Cancer Registry, Ferrara, Italy.

[7]Tarragona Cancer Registry, Tarragona, Spain.

[8]Northern Ireland Cancer Registry, Belfast, Northern Ireland.

[9]Basque Country Cancer Registry, Department of Health, Vitoria-Gasteiz, Spain.

[10]Thames Cancer Registry, King's College London, Cancer Epidemiology and Population Health, London, UK

[11]Icelandic Cancer Registry, Icelandic Cancer Society, Reykjavik, Iceland.

[12]Belgian Cancer Registry, Brussels, Belgium.

[13]Cancer Registry of Republic of Slovenia, Institute of Oncology Ljubljana, Slovenia.

[14]IKZ Integraal Kankercentrum Zuid, Eindhoven, The Netherlands

ACKNOWLEDGMENTS

The research leading to these results has received funding from the European Union's Seventh Framework Programme ([FP7/2007-2013] [FP7/2007-2011]) under grant agreement n° LSSH–CT–2008–21 9453.

The authors wish to thank all colleagues who took the time to complete the questionnaire.

Austria: Austrian National Cancer Register Cancer Registry, Cancer Registry of Tyrol. Belarus: Childhood Cancer Subregistry, Republic of Belarus. Belgium: Belgian Cancer Registry. Bulgaria: Bulgarian National Cancer Registry. Croatia: Croatian National Cancer Registry. Czech Republic: Czech National Cancer Registry. Denmark: Danish Cancer Registry. Estonia: Estonian Cancer Registry. Faroe Islands: Faroese Cancer Registry. Finland: Finnish Cancer Registry. France: Registre des Tumeurs du Doubs, Registre des Cancers du Haut-Rhin, Registre des Cancers du Tarn, Registre des cancers de Loire-Atlantique et de Vendée, Registre Général des Cancers en Région Limousin, Registre des Cancers du Bas-Rhin, Registre des Cancers de la Manche, Registre des Tumeurs de l'Hérault, Registre du Cancer de l'Isère, Cancer généraux- de Gironde, Registre général des cancers de Lille et de sa région, Registre du Cancer de la Somme, Registre finistérien des tumeurs digestives, Thyroide-Marne Ardennes, Hémopathies Malignes- Basse Normandie, Registre Bourguignon des Cancers Digestifs, Registre National des

* Corrsponding author. Address: Piedmont Cancer Registry, CPO, Via San Francesco da Paola 31, 10123 Torino, Italy

E-mail address: roberto.zanetti@cpo.it

Tumeurs Solides de l'Enfant, Registre des hémopathies malignes de la Gironde, Registre national des leucémies de l'enfant, Registre des Hémopathies Malignes en Côte d'Or. Germany: Krebsregister Rheinland-Pfalz, Epidemiologisches Krebsregister NRW - Nordrhein-Westfallen, Krebsregister Bremen/Registerstelle, Saarland Cancer Registry, Hamburgisches Krebsregister, Krebsregister Schleswig-Holstein, Tumorregister München, Epidemiologisches Krebsregister Niedersachsen, Bevölkerungsbezogenes Krebsregister Bayern, German Childhood Cancer Registry. Hungary: Hungarian Pediatric Cancer Registry. Iceland: Icelandic Cancer Registry. Ireland: National Cancer Registry of Ireland. Italy: Registro Tumori Provincia di Sondrio, Siracusa Territorial Registry of Pathology, Registro Tumori Toscano (R.T.T), Registro Tumori della Provincia di Modena, Registro Tumori del Piemonte, Provincia di Biella, Registro Tumori della Provincia di Ferrara, Registro Tumori del Veneto, Piedmont Cancer Registry, City of Turin, Registro Tumori della Provincia di Ragusa, Registro Tumori della Romagna, Registro Tumori di Parma, Registro Tumori del Friuli Venezia Giulia, Registro Tumori Regione Liguria, Registro Tumori Provincia di Mantova, Registro Tumori della Provincia di Nuoro, Registro Tumori di Trento, Registro Tumori Alto Adige, Registro Tumori di Milano, Registro Tumori Reggiano , Registro Tumori di popolazione della provincia di Latina, Registro dei Tumori Infantili del Piemonte. Lithuania: Lithuanian Cancer Registry. Malta: Department of Health Information and Research. Netherlands: Eindhoven Cancer Registry, Netherlands Cancer Registry. Norway: Cancer Registry of Norway. Poland: Greater Poland Cancer Registry, Rzeszow Regional Cancer Registry, Warsaw Cancer Registry, Pomeranian Registry at Regional Oncology Centre in Gdansk, Holycross Cancer Registry, Polish Cancer Registry, Lower Silesian Cancer Registry. Portugal: Registo Oncológico Regional dos Açores , Registo Oncológico Regional Sul, Registo Oncologico Regional do Norte – RORENO. Romania: Cluj County Cancer Registry, Timisoara Regional Cancer Registry. Serbia: Cancer Registry of Central Serbia. Slovak Republic: National Cancer Registry of the Slovak Republic. Slovenia: Cancer Registry of Slovenia. Spain: Unitat d'Epidemiologia i Registre de Càncer de Girona, Registro de Cáncer de Murcia, Registro de Cáncer de Albacete, Basque Country Cancer Registry, Tarragona Cancer Registry, Registro de Cáncer de la Rioja, Registro Poblacional de Cáncer de la Comunidad Autónoma de Canarias, Navarra Cancer Registry, Mallorca Cancer Registry, Registro de Tumores del Principado de Asturias. Sweden: South East Sweden Cancer Registry, Swedish Cancer Registry. Switzerland: Registro Tumori Cantone Ticino, Zentralschweizer Krebsregister Luzern, Registre Genevois des Tumeurs, Registre Vaudois des Tumeurs, Registre Neuchâtelois des Tumeurs, Kantonales Krebsregister Graubünden und Glarus, Registre Valaisan des Tumeurs, Krebsregister Kanton Zürich, Registre Fribourgeois des Tumeurs, Swiss Childhood Cancer Registry. Turkey: Izmir Cancer Registry. UK: Northern Ireland Cancer Registry, South West Public Health Observatory, Trent Cancer Registry, West Midlands Cancer Intelligence Unit, Scottish Cancer Registry, Eastern Cancer Registration & Information Centre, Thames Cancer Registry, Welsh Cancer Intelligence & Surveillance Unit (W.C.I.S.U.), Childhood Cancer Research Group.

ABSTRACT

The mission of a cancer registry is to provide complete and reliable incidence data with a short delay. Methods for monitoring completeness and timeliness are available to registries ranging from less to more complex. We wanted to know which methods are currently in use among cancer registries and to compare results with those obtained in a previous survey conducted in year 2006.

Methods We launched a new survey with questions on type of registry, completeness methods used and time and type of result dissemination. We sent the questionnaire to all general (GCR) and specialised (SCR) registries active in Europe, including the 27 countries of the European Union, the candidate members, Norway and Switzerland, from the list made available by the European Network of Cancer registries (ENCR).

Results With a response rate of 65.8% among GCR and 58.3% among SCR, we obtained 116 registries (population covered: 280 millions) available for analysis. The most common methods used were trends comparison (79%), and mortality–incidence ratio (above 60%). More complex methods resulted less used: capture-recapture (30%), the flow method (18%), and MIAMOD/PIAMOD (14%).
Median time for completing the incidence was 18 months, but with wide variation. Result dissemination delay was shorter, although more than one third (36.3%) declared to not publish their results on own, but only contributing to larger national or international data repositories and publications.

Conclusions Cancer registries should further improve the practice of measuring their completeness and should shift from traditional to more modern quantitative methods.

Words: 246

KEYWORDS: cancer registry, completeness, timeliness, flow methods

INTRODUCTION

The main goal of a population-based cancer registry is to constantly collect information on all cancer cases occurring in a population resident in a defined area. Disregarding the amount of information a registry can collect for each case, an incomplete collection of cases is of limited use. Completeness of registration – the extent to which all the incident cases are identified and included in the registry collection - remains therefore the first and principal test for a cancer registry to pass: only a complete registration can produce incidence rates and statistics close to their true values. Nowadays, when data collection is supported by a large availability of different sources, coming from automated treatment of data mainly designed for administrative purposes, this task should be relatively easy. However, only a throughout and painstaking monitoring with different methods can assure and document that this goal has been reached. Indeed, incompleteness is often differentially affecting data collection: for example case finding is often more difficult in 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 to have a certain type of tumour to be reported, resulting in different completeness of registration by cancer site. It is also worth considering that incompleteness in case ascertainment not only biases the incidence statistics, but, together with incompleteness in follow-up also affects survival and prevalence figures. [2]
Several methods for inspecting completeness of registration have then been devised to detect where cases are possibly missed, each of them addressing a particular aspect of the problem. And each of them with their pros and cons, but substantially used with the general and informal recommendation to apply more than one to the data to get a better picture from different sides.

In brief, there are several methods to evaluate the completeness: some are traditional, simpler and less statistically complicated, other, more complex and computationally difficult. More in general it is useful to categorize those methods in two groups:

- Qualitative (or semi-quantitative) methods; and
- Quantitative methods

Reviews of these methods can be find in Parkin and Bray [3, 4] and Schmidtmann and colleagues [5], and in the following briefly summarised.

The **qualitative or semi quantitative** methods provide some indications of the degree of completeness relative to the other registries or over time, but do not actually quantify the number of cases missing. They are:

1. Historic Data Methods [6]
    a. Stability of incidence rates over time
    b. Comparison of incidence rates in different populations
    c. Shape of age-specific curves
    d. Incidence rates of childhood cancers
2. Mortality:Incidence ratios [6]
3. Number of sources / notifications per case [6]
4. Microscopic verification of diagnosis [6]
5. MIAMOD/PIAMOD (Mortality and Incidence Analysis MODel, Prevalence and Incidence Analysis MODel) by comparison of observed and model estimated quantities [7].

The **quantitative** methods provide a numerical evaluation of the extent to which all eligible cases have been registered, and they are:

1. Independent case ascertainment [6]

2. Capture-recapture methods [8, 9]
3. Death certificate methods,
    a. DCN / M:I method [6]
    b. Flow method [10]

The current use of these methods among the European registries was explored in a survey conducted between 2005 and 2006 with the main objective to find out whether cancer registries actually estimated completeness, with which methods and how they eventually disseminated their results. The survey's results, published in 2009 [5], showed that the majority of cancer registries used only qualitative methods, only a minority quantitative methods (about 20%) such as capture-recapture and flow method, and only few made comparisons among methods and made their result available to the public. However, the low percentage of respondents among registries (29%) poses some limitation to the generalisation of results.

Therefore, in the framework of the Eurocourse project [http://www.eurocourse.org] we decided to replicate the survey, improving the registries compliance, and including more questions to the original questionnaire on availability of data for identifying "used" versus "intended" methods. We also added a section on timeliness of results publication, since we believed that the problem is connected to the completeness. Indeed, the need of reaching an almost perfect completeness, often has been advocated by the registries for further delaying dissemination of their results.

MATERIALS AND METHODS

The target population was the population-based cancer registries active in Europe, both general (GCR) or specialised (SCR). Operationally, we included those registries based in the 27 countries of the European Union, considering also the candidate members, Norway and Switzerland, contributing with recent data to the database of the European Network of Cancer Registries (ENCR: http://www.encr.com.fr/). The initial population target was set to 179 registries, out of 206 in the ENCR member list, including SCR. The difference was due to the fact that the larger list included registries not yet or not any more active (i.e. with available recent data). SCR included in the survey were those collecting information only on patients with a defined age (childhood), or on a specific cancer site (for example, digestive system, mesothelioma, breast).

The questionnaire used for the previous survey [5] was updated and structured in four sections. In the first section there were questions useful for describing the type of activity (specialised or general), the institutional setting of each registry, its characteristics as population size and period covered. The second section explored the availability and the current practice of collection of this information useful for calculating completeness under different methods. Finally, the third section, collected information on methods, if any, used by each registry for estimating its completeness, who and when the estimation was performed, where eventually published, or the reasons for not performing the estimation. In this section, we also asked registries to provide a self assessed estimate for their completeness. Furthermore, we investigated the availability of software, performance of method comparisons, references, contact details and interest in feedback. A fourth section investigated the timeliness of data publication under different circumstances.

We firstly sent an invitation letter and posted the questionnaire on the ENCR website in January 2011, addressing 179 cancer registries from 32 European countries. A reminder was sent at the end of February for increasing the number of respondents. The returned questionnaire were uploaded in a MySQL database [11], and finally exported for analysis in a SAS 9.2 format [12]. We computed relative and absolute frequencies, presenting results in tables and graphs. Registries were grouped by country or by continental areas according to the definitions of the United Nation Population Division [13].

RESULTS

We contacted 179 European cancer registries (among which 24 specialised) and 116 (64.8 %) replied: 102 among the GCR with a response rate of 65.8% and 14 among the SCR, with a response rate of 58.3%. The population covered by the respondent registries is more than 280 millions, corresponding to about 50% of the 32 countries where one or more registries was invited to participate. In Table 1, we presented the respondents registries by country and continental area as defined by the United Nation Population Division [13]. Among the respondent registries, the largest group (62%) started their activity after 1980 and forty-one percent covered a population of 1 million inhabitants or less (Table 2). Forty-six percent of the respondents had less than 6 full-time-equivalent persons in staff.

Completeness

On total eighty-eight percent of registries affirmed to check completeness with some method: respective proportions were 86% in GCR, and 100% in SCR (Table 3). Reasons advanced by the 14 registries (all general) that did not estimate completeness were: lack of time, software and 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 mortality–incidence ratio (above 60%); slightly fewer registries (30%) used methods based on Death Certificate Notification, including those based on the formula proposed by Ajiki [13]. Complex methods, or better those methods that allowed for quantitative evaluation of incompleteness, such as capture-recapture [8, 9] were used by 30% of registries, the flow method [10] by 18%, and MIAMOD/PIAMOD [6] only by 14%. (Table 4)

Regional differences in the used methods were small, but quantitative methods were used more frequently by Northern registries, with the exception of the MIAMOD/PIAMOD [7] method that, although not frequently used, was used more by registries in the South Europe area (Figure 1). The use of the flow method was also limited by the lack of information on date of registration in 13% of registries.

Since one of the barriers for estimating completeness was lack of specific software, we asked their availability and use of software (Table 5).

In general, epidemiologists and statisticians are those who perform completeness estimates, while computer scientists, MD, registrars and external researchers are far less participating (Table 6).

Among those who estimated ascertainment completeness, only 20.6% published their results on a peer reviewed journal, while the majority used internal technical reports (40.2%), but a vast proportion did not published their result anywhere (36.3%).

A separate question asked about the registry self assessment of completeness. For registries that affirmed to measure completeness, the answer was presumably based on the results of this measurement (Table 7); those that declared to not routinely measure the completeness did not answer this question, apart of two which, with apparent contradiction, declared to have a completeness over 90%.

Timeliness

Median time for completing the last year of incidence was 18 months, but with huge variations. After case ascertainment completion, latencies for publishing the data (at local or national level) and for sending them to international databases seemed to be quite short, for the cancer registry

standards, but some registries (twenty-one) did not answer the questions relate to the dissemination of results, with the suspect that somehow this important part of the registry's activity received less attention. Data dissemination and sharing of data with the national or international repositories required an additional 4 months, ranging from 1 to 24 months (Table 8). We did not observe any significant association between measuring completeness with quantitative methods and publishing data sooner.

DISCUSSION

The proportion of registries that currently evaluate their completeness is reasonably high, almost 88%, even higher than the 86% observed in the previous survey conducted in 2006 [5]. Moreover, the proportion of respondents to the present survey is considerably higher than the previous one, when only 56 registries filled the questionnaire: probably the most motivated and best performing. The methods used for estimating completeness are still at large those based on simple comparisons with previous own data or with those of other registries. The use of quantitative methods is slightly increased since the 2006 survey, however they did not yet become the prevalent methods. In particular, a "country" effect is recognisable where the flow method [10] was used prevalently in Northern countries and the MIAMOD/PIAMOD method [7] in Southern countries where the two methods were respectively firstly devised and used.

The self assessed completeness (Table 7) is overall optimistic; in particular it is probably overestimated for cancer registries which affirmed to reach high completeness, even if they did not use quantitative methods to estimate it. In our opinion, the estimates of completeness assessed by cancer registries which adopted quantitative methods are more reliable. Finally the high degree of completeness reached by the two cancer registries which do not estimate it seems apparently inconsistent.

Timeliness is also connected to completeness, and increased latency in delivering data is often attributed to the burden of work needed to reach high completeness. However, we did not observe such association in the answer of the registries, since the registries with high completeness where also those with less latency in producing and disseminating their data. This could also be due to the fact that the flow method provides estimates of completeness of registration in a given year at successive time intervals, and therefore provides indirectly information on the timeliness of registration procedures, so being monitored more closely.

The generalisation of our results is granted by the high response rate and by the fact that in practice all European countries are represented, with few exceptions. Some limitation in interpreting the results can be due to the misunderstanding of some questions that cannot be excluded, and by the subjective setting of the answers.

In conclusion, our results confirm in a larger and more updated sample, those from the previous survey and the need, for the registries, of disseminating quantitative methods. The international groups of registries, such as ENCR and IACR, as well as research consortia using registries' data, should support with recommendations, facilitate with standardisation of methods, and further spur cancer registries in estimating their completeness and timeliness with quantitative methods.

REFERENCES

1. Quaglia A, Tavilla A, Shack L et al. The cancer survival gap between elderly and middle-aged patients in Europe is widening. Eur J Cancer 2009 Apr; 45(6):1006-16. Epub 2008 Dec 31.
2. Brenner H, Hakulinen T, Population-based monitoring of cancer patient survival in situations with imperfect completeness of cancer registration. Brit J Cancer 2005; 92:576-9.
3. Bray F, Parkin DM. Evaluation of data quality in the cancer registry: principles and methods. Part I: comparability, validity and timeliness. Eur J Cancer. 2009 Mar;45(5):747-55. doi: 10.1016/j.ejca.2008.11.032. Epub 2008 Dec 29
4. Parkin DM, Bray F, Evaluation of data quality in the cancer registry: Principles and methods Part II. Completeness. Eur J Cancer 2009; 45:756-64.
5. Schmidtmann I, Blettner M**,** How do cancer registries in Europe estimate completeness of registration? Methods Inf Med 2009; 48(3):267-71.
6. Parkin DM, Chen VW, Ferlay J, Galceran J, Storm HH and Whelan SL. Comparability and Quality Control in Cancer Registration. IARC Technical Report No. 19. 1994, IARC, Lyon
7. Verdecchia A, Capocaccia R, Egidi V, and Golini A. A Method for the Estimation of Chronic Disease Morbidity and Trends From Mortality Data. Stat Med 1989;8(2):201-16.
8. Robles SC, Marrett LD, Clarke EA, Rish HA. An application of capture-recapture methods to the estimation of completeness of cancer registration. J Clin Epidemiol 1988; 41: 495-501.
9. Schouten LJ, Straatman H, Kiemeney LA, Gimbrere CH, Verbeek AL. The capture-recapture method for estimationof cancer registry completeness:a useful tool? Int J Epidemiol 1994; 23: 1111-6.
10. Bullard J, Coleman MP, Robinson D, Lutz JM, Bell J, Peto J. Completeness of cancer registration: a new method for routine use. Brit J Cancer 2000; 82(5):1111-6.
11. MySQL 5.1 Reference Manual: http://dev.mysql.com/doc/refman/5.1/en/index.html. Retrieved Nov. 2012.
12. SAS Institute. Base SAS 9.2 Procedures Guide, Volumes 1-3. Cary, NC, 2009
13. UN Population Division. Definition of Major Areas and Regions. URL: http://esa.un.org/unpd/wup/CD-ROM_2009/WPP2009_DEFINITION_OF_MAJOR_AREAS_AND_REGIONS.pdf
14. Ajiki W, Tsukuma H, Oshima A. Index for evaluating completeness of registration in population-based cancer registries and estimation of registration rate at the Osaka Cancer Registry between 1966 and 1992 using this index. Nihon Koshu Eisei Zasshi 1998; 45:1011–7.
15. Colonna M, Grosclaude P, Faivre J et al. Cancer registry data based estimation of regional cancer incidence: application to breast and colorectal cancer in French administrative regions. J Epidemiol Commun H 1999; 53:558-64.

COUNTRY	Respondents	Covered Population
Denmark	1	
Estonia	1	
Faroe Island	1	
Finland	1	
Iceland	1	
Ireland	1	
Lithuania	1	
Norway	1	
Sweden	2	
UK	9	
Total North	**19**	**79423768**
Austria	2	
Belgium	1	
France	20	
Germany	10	
Switzerland	10	
The Netherlands	2	
Total West	**45**	**103954016**
Belarus	1	
Bulgaria	1	
Czech Republic	1	
Hungary	1	
Poland	7	
Romania	2	
Slovakia	1	
Total East	**14**	**55672762**
Croatia	1	
Italy	21	
Malta	1	
Portugal	3	
Serbia	1	
Slovenia	1	
Spain	10	
Total South	**38**	**44450723**
TOTAL	**116**	**283501269**

Table 1. Respondent registries by country and population coverage by European area

Year of starting activity	GCRs	SCRs	Total
Old (Year Start<=1980)	36	8	44
Intermediate (1980 < Year Start<=2000)	54	5	59
New (Year Start>2000)	12	1	13
Population covered			
Large (Pop Covered>2mln)	39	4	43
Medium (1mln<Pop Covered<=2mln)	20	5	25
Small (Pop Covered<=1mln)	43	5	48
Number of Staff (full time Equivalent)			
Up to 5 FTE	44	9	53
6-10 FTE	32	5	37
10-20 FTE	8	0	8
20-30 FTE	6	0	6
30-40 FTE	5	0	5
More than 40 FTE	5	0	5

Table 2. Number of respondent general (GCR) and specialised (SCR) cancer registries by first year of activity, population covered and number of staff in Full Time Equivalent (FTE).

	YES	%	NO	%	Total
General CR	88	86%	14	14%	102
Specialized CR	14	100%	0	0%	14
Total	102	88%	14	12%	116

Table 3. Practices of measuring completeness in general and specialized CRs

METHOD	No		Yes		Tot	% Yes
	GCR	SCR	GCR	SCR		
Historical Comparison [6]	20	1	68	13	102	**79%**
Comparison with reference registry [6]	34	5	54	9	102	**62%**
Comparison with reference registry (indirect standardization) [6]	57	11	31	3	102	**33%**
DCN method [6]	57	13	31	1	102	**31%**
DCN method (Ajiki's formula) [14]	79	14	9	0	102	**9%**
M/I ratio: comparison with other registries/ national average [6]	26	12	62	2	102	**63%**
M/I ratio: comparison with own registry in previous year(s) [6]	20	11	68	3	102	**70%**
Log-linear models [15]	77	14	11	0	102	**11%**
Independent case ascertainment [6]	58	10	30	4	102	**33%**
Flow method [10]	71	13	17	1	102	**18%**
MIAMOD / PIAMOD [7]	74	14	14	0	102	**14%**
Capture Recapture [8,9]	61	10	27	4	102	**30%**
Other	78	11	10	3	102	**13%**

Table 4. Methods used by Cancer Registries for estimating completeness (multiple answers allowed)

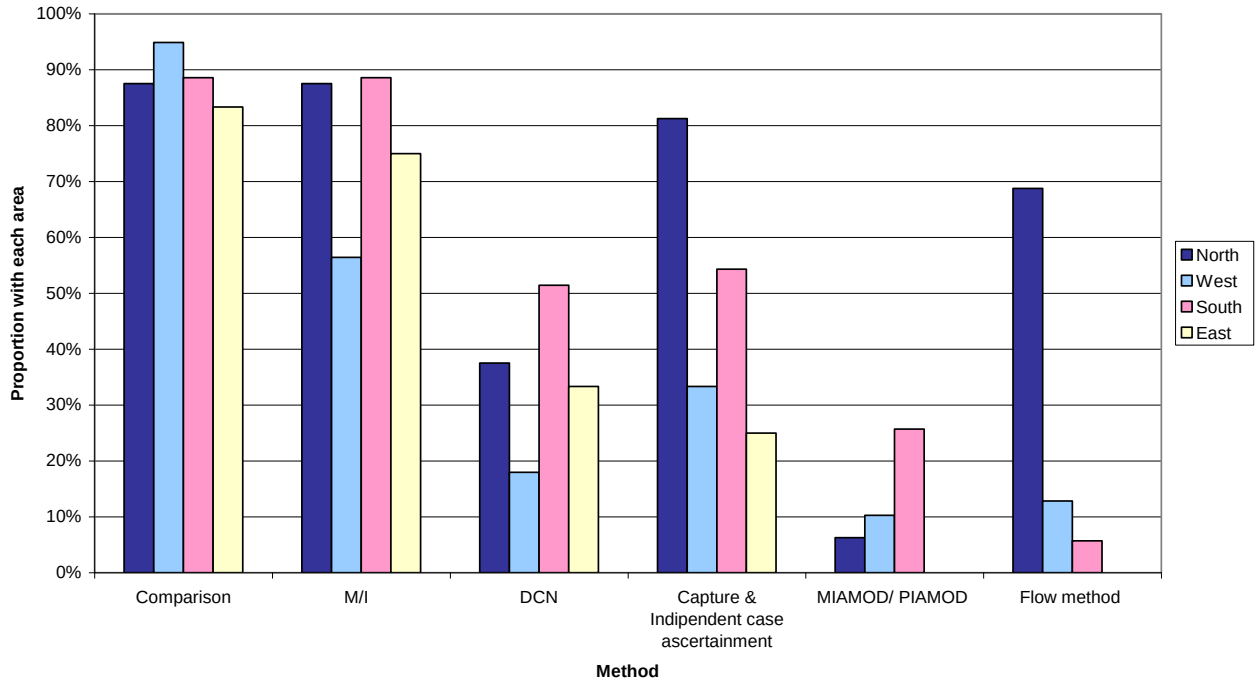

Figure 1. Use of main methods for estimating completeness in the European areas

	NO		YES		Total		%
	GCR	SCR	GCR	SCR	GCR	SCR	YES
Historical Comparison [6]	50	11	38	3	68	13	**51%**
Compare incidence with incidence in reference registry [6]	51	11	37	3	54	9	**63%**
Comparison with reference registry (indirect standardization) [6]	68	12	20	2	31	3	**65%**
DCN method [6]	70	13	18	1	31	1	**59%**
DCN method (Ajiki's formula) [14]	79	14	9	0	9	0	**100%**
M/I ratio: compute and compare with own registry in previous year(s) [6]	39	11	49	3	68	3	**73%**
M/I ratio: compute and compare with other registries/ national average [6]	52	12	36	2	62	2	**59%**
Log-linear models [15]	82	14	6	0	11	0	**55%**
Independent case ascertainment [6]	73	13	15	1	30	4	**47%**
Flow method (Bullard) [10]	76	13	12	1	17	1	**72%**
MIAMOD / PIAMOD [7]	74	14	14	0	14	0	**100%**
Capture recapture [8, 9]	73	13	15	1	27	4	**52%**
Other	79	13	9	1	10	3	**77%**

Table 5. Availability of specific software for estimating completeness according to methods.

Professionals	Registries
Epidemiologist	63
Statistician	42
Computer scientist	19
MD	19
Registrar / Documentalist	14
External researcher	16

Table 6. Which Professional performs completeness estimates (more than one answer possible)

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

Table 7. Number of registries according to self assessed percentage of completeness

	N	Mean	Median	Minimum	Maximum
Complete one 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 body	75	4	2	1	24
Provide data for European Database	88	4	4	1	24
Provide data for Cancer Incidence in Five Continents	86	4	4	1	25

Table 8. Latency for completing one year of case ascertainment and releasing data (in months)