"Liberating information, improving outcomes"

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EUROCOURSE project: Cancer Registry Data for Research

Achievements and pitfalls: the trade off between completeness and timeliness

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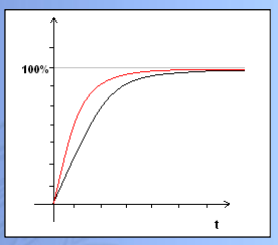
- Completeness: one of the aspects of the quality of data
- Timeliness: one of the aspects of the quality of the system that produces the data and makes them available for users (researchers, doctors, patients, planners)
- Between the two (completeness and timeliness) is it a matter of
  - Trade-off
    or
  - Convergence

?

Three main phases are time consuming (and potentially delay generating)

- Data collection



Last percentiles of information always come late…

But, with automation of sources and data transmission, the most of information comes sooner and in a more rapid way.

- Data processing
- Data analyses and publication

These two phases should benefit from technology and from maturity (of both, the registration milieu and the single Registries)

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- May be a major point influencing the timeliness is the fact that many CRs are small shops, where the same few people perform all the different tasks.
- In this case it is natural that they do the subsequent steps in series and not in parallel, so that the duration (and the delay) of each influences the next.

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…If it is true that one of the causes of delay is our concern about completeness, let's have a look on what we are doing for assessing the completeness…

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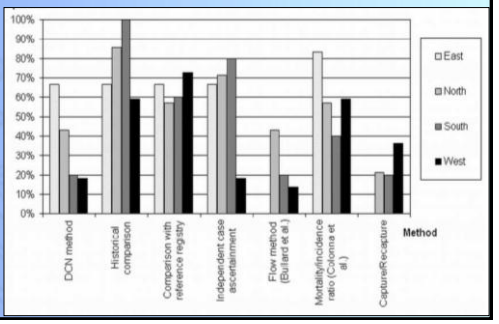
Completeness: the previous survey

In 2005 I. Schmidtmann and M. Blettner (Mainz, Germany) performed a Survey on completeness in registration among European Registries (*Schmidtmann I, Blettner M. How do cancer registries in Europe estimate completeness of registration? Methods Inf Med 2009; 48: 267-71.*)

- They contacted **195** Registries; 56 (29%) completed the questionnaire.
- **48** cancer registries stated that they estimated completeness, **8** did not.
- Among the methods listed in the questionnaire, the most common resulted: historical comparison and comparison with reference registry.
- There were regional difference in the choice of method.
- Few registries confirmed the availability of dedicated software.

	METHOD IS APPLIED					
	No information or never		Routine use		Special occasion	
METHOD	N	%	N	%	N	%
Flow method (by J. Bullard)	38	79	5	10	5	10
Capture recapture	36	75	5	10	7	15
DCN method	22	46	14	29	2	4
Historical Comparison	15	31	35	73	0	0
Independent case ascertainment	28	58	9	19	13	27
Mortality/incidence ratio (by M. Colonna)	15	31	18	38	10	21
Comparison with reference registry	19	40	24	50	7	15



The new EUROCOURSE survey

- A WP3 Working Group leaded by I. Schmidtmann and R. Zanetti decided to update the previous survey.
- The new questionnaire (an evolution of the previous one) concerned the practice of both, monitoring the completeness and assessing the timeliness
- The members of the WG (Binder-Foucard F., Bordoni A., Coza D., Ferretti S., Galceran J., Gavin A., Larranaga N., Robinson D., Rosso S., Schmidtmann I., Tryggvadottir L., Van Eycken E., Zadnik V.) acted as national/regional facilitators for encouraging respondance.
- The survey was completed in January/February 2011 and we collected **114** questionnaires.

  Problems with the definition of the denominator:

  - Different definition of Europe: EU (Member, Candidates, Potential Candidates); European non EU countries; etc
  - Defining CR within defined countries:
    - Known/not known/imperfectly known (see ENCR address list)
    - Active/not active (never, no longer, not yet)
    - General/specialized
    - National/Regional/Regional + National

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Description of the respondents

- Respondence rate = $\frac{Q}{N_1, N_2, ..., N_n} = \frac{114}{150;206}$ → **[76%; 55%]**
- The population covered by the respondents CRs is **283,501,269** (~50% of the population of the countries where CRs were invited to participate).

COUNTRY	ANSWERS	COUNTRY	ANSWERS
Austria	2	Lithuania	1
Belarus	1	Malta	1
Belgium	1	Norway	1
Bulgaria	1	Poland	7
Croatia	1	Portugal	3
Denmark	1	Romania	2
Estonia	1	Serbia	1
Faroe Islands	1	Slovak Rep	1
Finland	1	Slovenia	1
France	20	Spain	10
Germany	10	Sweden	2
Hungary	1	Switzerland	10
Iceland	1	The Netherlands	2
Ireland	1	UK	9
Italy	20		

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Results (limited to General Cancer Registries)

Completeness

- Among the 100 General Registry that responded:
- **86** registries say they estimate the completeness of registration, occasionally or routinely. They filled in the questionnaire and described the methods they use.
- **14** registries said the do not estimate their completeness, for one or more of the following reasons:
  - Not necessary (2);
  - Too much time required (2);
  - No software available (5);
  - Nobody in the registry capable doing it (4);
  - Other (7).

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Results (limited to General Registries)

FREQUENCY OF USE OF VARIOUS METHODS (multiple answers possible)

METHOD	No	Yes	Tot	% Yes
Historical Comparison	20	66	86	76,7%
Compare incidence with incidence in reference registry	33	53	86	61,6%
Comparison with reference registry (indirect standardization)	55	31	86	36,0%
DCN method	55	31	86	36,0%
DCN method (by Ajiki's formula)	77	9	86	10,5%
M/I ratio: compute and compare with own registry in previous year(s)	19	67	86	77,9%
M/I ratio: compute and compare with other registries/ national average	25	61	86	70,9%
Log-linear M/I modelled (by M. Colonna)	75	11	86	12,8%
Independent case ascertainment	56	30	86	34,9%
Flow method (by J. Bullard)	69	17	86	19,8%
MIAMOD / PIAMOD (by A. Verdecchia)	72	14	86	16,3%
Capture recapture	59	27	86	31,4%
Other	76	10	86	11,6%

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Results (limited to General Cancer Registries)

- Classification of methods with respect to various criteria

	Traditional / New	Direct Method	Statistical Complexity*	Ability to detect single case	Theoretically unbiased	Observed in The Survey YES	% YES
Comparison (Historical comparison, Compare incidence with incidence in reference registry, Comparison with reference registry -indirect standardization)	Traditional	No	E E E	No	No	**77**	**89.5**
M/I (M/I1:compute and compare with own registry in previous years, M/I2:compute and compare with other registries/ national average, Log-linear models by M. Colonna)	Traditional	No	E E C	No	No	**72**	**83.7**
DCN (DCN method, DCN method with Ajiki's formula)	Traditional	Yes	E E	Yes	No	**34**	**39.5**
Capture/recapture & Independent case ascertainment	New	Yes	C C	Yes	Yes	**42**	**48.8**
MIAMOD / PIAMOD (by A. Verdecchia)	New	No	C	No	No	**14**	**16.3**
Flow method (by J. Bullard)	New	Yes	C	Yes	Yes	**17**	**19.8**

*** E=Easy; C=Complex**

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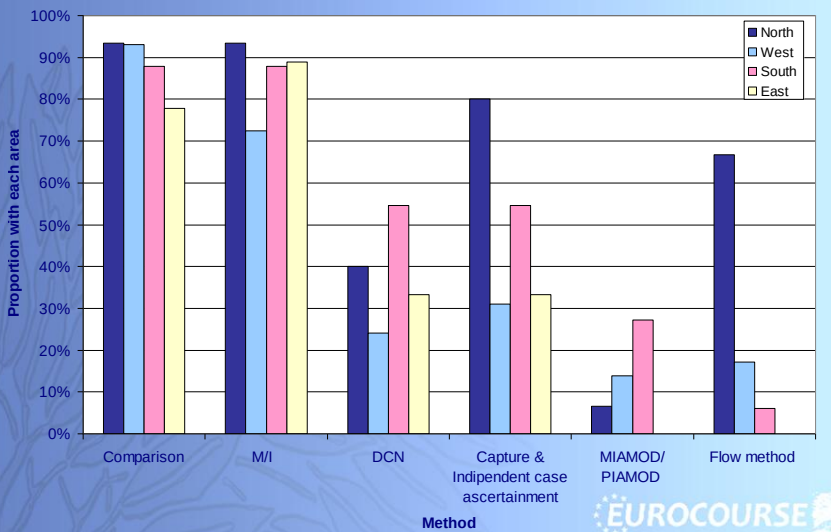
Results (limited to General Cancer Registries)

- Regional differences in the choice of methods



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Results (limited to General Cancer Registries)

- The percentage of completeness (estimated by each registry) is distributed as follow:

Estimation of completeness of registry

Percentage of Completeness	Frequency
No answer	1
<50%	0
50% to <60%	0
60% to < 70%	0
70% to < 80%	2
80% to < 90%	7
90% to < 95%	25
>95%	51

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Conclusions

Completeness

- Since 2005 (previous survey), apparently no revolutions with respect to the matter
- A minority (not a negligible fraction) of Registries doesn't seem to be interested in (or able to) assessing their completeness
- Traditional, simple, indirect methods remain the most popular
- Newest methods, more complex, more "computational" (and requiring specific software) are still used by a minority of registries
- Registries that appear more attentive to the matter, and set a large battery of different methods (including the more complex ones), are in some case reaching a more "pessimistic" conclusion about their completeness (less than 95%, and even less than 90%) than Registries that use the simplest methods
- Assessing completeness seems to be an attitude little related to the size and the running time of the Registry; a country effect seems to play just for UK (flow method)

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Results (limited to General Cancer Registries)

Timeliness

Latency for releasing data (time in months)

	N	Mean	Median	Minimum	Maximum
Publish printed report	78	6	4	1	30
Publish data on Internet	78	5	3	1	30
Forward data to national body	65	4	2	1	24
Provide data for European Database	79	4	4	1	24
Provide data for Cancer Incidence in Five Continents	78	4	4	1	25

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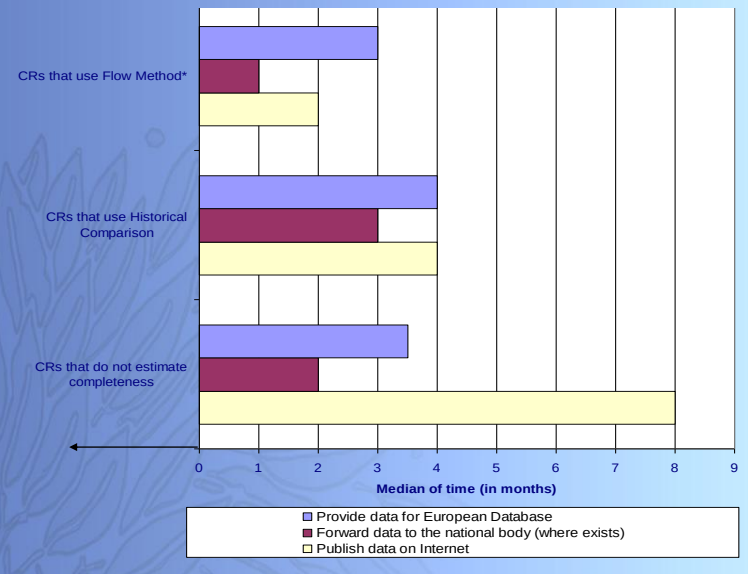
Results (limited to General Cancer Registries)



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Conclusions

Timeliness

- Latency for data collection and processing. Some results are quite incoherent (probably due to some questions that revealed misleading).

  It is difficult to define and measure processes that are different from registry to registry

- Latencies for publishing the data (at local or national level) and for sending them to the international Databases seem to be quite short

- No strong association between measuring completeness with more sophisticated methods and publishing data sooner.

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THANK YOU FOR YOUR ATTENTION

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