RARECARE
Surveillance of Rare Cancers in Europe

Cancer registries and rare cancers: quality of data, supplementary information
RARECARE WP6 3rd meeting
National Institute of Public Health - Warsaw 25th March 2010

Minutes

Name	CR/Country
1. Fani Škrlec	Slovenia
2. Otto Visser	Amsterdam / The Netherlands
3. Jerzy Slowinski	Silesia
4. Annemarie Eeltink	Comprehensive Cancer centre North East/The Netherlands
5. Kathleen England	Malta
6. Margid Magi	Estonia
7. Jaume Galceran	Tarragona/Spain
8. Kris Henau	Belgium CR
9. Cindy De Gendt	Belgium CR
10. M Isabel Izarzugaza	Basque Country
11. Valérie Jooste	Cote D'Or Digestive
12. Anne-Marie Bouvie	Cote D'Or Digestive
13. Michel Coleman	LSHTM/UK
14. Fani Škrlec	Slovenia
15. Reysard Mezyk	Kielce
16. Lukasz Fortuna	Kielce
17. Nadine Zielonke	Austria
18. Andrea Bordoni	Ticino (Switzerland)
19. Michel Lutz	National Institute for Cancer Epidemiology and Registration (NICER)
20. Magdalena Bielska - Lasota	National Institute of Public Health - Poland
21. Gemma Gatta	Istituto Nazionale dei Tumori, Italy
22. Annalisa Trama	Istituto Nazionale dei Tumori, Italy
23. Riccardo Capocaccia	Istituto Superiore di Sanità, Italy
24. Carmen Martinez	Escuela Andaluza de Salud Pública, Spain
25. Melchor Rodriguez	Escuela Andaluza de Salud Pública, Spain
26. Juan Manuel	Escuela Andaluza de Salud Pública, Spain
27. Gomez Ruiz	Escuela Andaluza de Salud Pública, Spain
28. Jan-Maarten van der Zwan	Comprehensive Cancer centre North East/The Netherlands

Gemma Gatta welcomed participants and shared the objectives of the meeting:

- To discuss the preliminary results of data quality check
- To plan for further analysis
- To disseminate the results
- To define possible recommendations for rare cancer registration
- To discuss for a seminar on rare cancers

Information on rare cancers available from the low resolution studies

Information on stage and treatment seems available. The information on stage is more complete than the one on treatment however there were issues related to the accuracy of the information on stage.

Before thinking to analyse survival by stage it was suggested to:

- select strictly CRs (set threshold for data quality indicators to select CRs)
- select rare cancers for which information on stage is easy to obtain and for which a wide accepted classification exists.
- consider another period of diagnosis for the analysis (in Switzerland CRs improved their data quality after the 2002). Look at the trend for quality indicators in CRs to select the period to consider for analysing survival by stage
- survival by stage should not be analysed for CNS tumours (in case an analysis by morphology would be better)

Data quality study

The objectives of the study were:

- To verify the diagnostic accuracy
- To assess the completeness of incidence
- To verify the quality of follow-up
- To verify the availability of information on stage, treatment and place of treatment

The study focused on rare tumours of the so called 'short list', a group of rare tumours with high priority. These tumours were selected because of their relevance for primary prevention, early diagnosis, diagnostic accuracy, quality of care, clinical research feasibility or because of their poor data quality in rare cancer registration (Tab 1).

Table 1. Rare tumours to be studied for data quality and reasons for their relevance.

Rare tumour	Primary prevention	Early diagnosis	Diagnostic accuracy	Quality of care	Clinical research feasibility	Poor data quality
Mesothelioma	**+++**	?	++	+	++	+
Liver angiosarcoma	**+++**	?	+	++	+	+
Sarcomas	++	++	**+++**	++	+	++
Oral cavity tumours	++	**+++**	+	++	++	+
CNS tumours	++	++	++	**+++**	++	++
Germ cell tumors	+	+	+	**+++**	+	+
Leukaemia	++	+	++	**+++**	+	++
Endocrine tumours	+	?	++	++	++	**+++**

+++ very high relevance, ++ high relevance; + relevant; ? no data on the efficacy

For the revision of the morphology and/or of the primary cancer site, the documents/files revised were the pathologic reports and the clinical dossiers **filed at cancer registry offices**.

The mortality files were reviewed **only** for mesothelioma, angiosarcoma of the liver and central nervous system tumours in order to check the vital status.

The period of diagnosis of cases revised was 1995-2002. The study focused on malignant tumours only (5th digit of the morphology codes ≥3).

Thirty four CRs from 14 different EU countries were included in the preliminary analysis.

A summary of the main results follow:

Mesothelioma long survivors

- (83%) confirmed as mesothelioma long survivors
- (12%) were mesothelioma not long survivors (22 lost to follow-up and 46 with death date changed
- (5%) were not mesothelioma long survivors

Pleura cancers different from mesothelioma

- 465/681 (68%) confirmed as pleura cancers. Out of these, 47 were mesothelioma

Malignant digestive endocrine tumour (MDET)

According to the criteria proposed 86 cancers were classified with a benign behaviour /1.

Topography	Behaviour				
	/1	/3	NA	deleted	Total
oesophagus	0	0	5	0	5
stomach	**13**	**17**	199	2	231
small intestine	**26**	86	503	3	618
colon	2	17	177	2	198
appendix	**18**	1	269	1	289
recto-sigmoid junction	1	0	12	0	13
rectum	**15**	8	161	3	187
anus and anal canal	1	0	5	0	6
liver	0	0	1	0	1
gallbladder	0	0	7	0	7
other, unspec parts of biliary tract	3	0	5	0	8
pancreas	6	8	92	2	108
thymus	1	0	0	0	1
Total	**86**	**137**	**1436**	**13**	**1,672**

CNS long survivors

- 343/705 (49%) confirmed as real long survivors
  - Real brain tumours survivors 282/705 (40%)
  - Not brain tumours long survivors 61/705 (9%)

- 337/705 (48%) were brain tumours not long survivors
  - 124 lost to follow-up
  - 213 death date changed

For 25 cases (3%) the information on the follow-up was missing. It will to be verified with CRs.

Leukemia

1214 cases of leukaemia NAS reviewed:
- (84%) confirmed leukaemia NOS
- 16 cases excluded from the incidence
- 5 cases specified CML: 3 typical and 2 atypical
- 219 cases were Other leukaemia/lymphoma

2378 cases of CML,NOS reviewed:
- 2009 cases (84%) confirmed CML, NOS
- 7 excluded from the incidence
- specified CML: 227 typical and 24 atypical (11%)
- 55 cases were Other leukaemia/lymphoma

Preliminary analysis of the impact of the revision on incidence and survival were performed only for few entities. However, the preliminary analysis showed that:

- Quality control of site and morphology was effective
- For many entities, indicators' estimates are not dramatically affected
- with the exception of some rare cancers (GIST, CML subtypes)
- and mostly for the first years of ICDO-3
- Follow-up revision is also important and should be improved in many cancer registries

Information on treatment and place of treatment

It is extremely difficult to collect information on all treatment however information on first line treatment is highly reliable
It is difficult to define the place of treatment since the health care system is different among countries. It would be better to address the problem of the place of treatment with study undertaken at country level. It could be possible to describe the place where the patients got the treatment.
In any case the collection of such information should be doe in collaboration with clinicians.

Course on rare cancers

Participants welcomed the news about the first course on rare cancers.
It was also suggested to promote the inclusion of rare cancers in the training course programme of national and international cancer registries associations.

Conclusions

1. There is a need for standard rules of coding and classification of rare cancers and for training of registrars
2. Promote training also of (specialized) registration clerks
3. Registration manuals should be improved
4. Identify quality checks specific for rare tumours
5. Include diagnosis in text as well as coded (or keep pathology report)
6. Consider the idea of having experts available at the registry
7. The RARECARE list of cancers should be used as a reference for coding (morphology and topography) of rare cancers
8. Setting recommendations it will be important to produce recommendations for CRs as well as for clinicians and pathologist. It is from the clinical and pathologic reports that CRs get their information.
9. Recommendations for rare cancers should be promoted in collaboration with national and international network of CRs

The meeting ended at 5.00 pm