

Minutes of the Meeting held in Granada, Spain on the 25th of March 2009.

Present:

Gemma Gatta, Samba Sowe, Annalisa Trama, Riccardo Capocaccia, Jean Michel Lutz, Torgil Moller, Anne-Marie Bouvier, Valérie Jooste, Jerzy Slowinski, Magdalena Bielska-Lasota, Ryszard Mezyk, Maja Primic-Žakelj, Sandra Deady, Jan Maarten Van der Zwan, Anne Marie Eeltink, Otto Visser, Margit Magi, Ricardo Gonzalez-Campora, Juan-Manuel Melchor, Maria-Jose Sanchez and Carmen Martinez-Garcia.

Unable to attend:

Jan Adolfson, Mats Lambe, Marc Maynadie, Adriano Giacomini and Wilhelm Oberaigner

1. Welcome, approval of the agenda, overview of the project and aims of the meeting

Participants were formally welcomed by Dr. Gemma Gatta in her quality as the project leader followed by a review and approval of the agenda and an overview of the project. Dr. Gatta outlined the followings as the main aims of the meeting:

- to discuss on how to improve data quality in rare cancers registration
- to agree on a common work for improving data quality
- to agree on a protocol for the check of the cases and the collection of further clinical information
- to plan a seminar on rare cancers data quality

2. Data quality analysis on rare cancers

Dr. Carmen Martinez-Garcia, leader of WP 6 (Cancer Registries and Rare Cancers: data quality and supplementary information) said the main objectives of her WP are to assess the validity, completeness and inter-registry standardisation of population-based cancer registry data on rare cancers and to improve the data quality and comparability of incidence, prevalence and survival of rare cancers among European population-based cancer registries (CRs). She said the difficulties in studying rare cancers, data quality and comparability could be associated to low number of cases, random variations in incidence and survival as well as in quality indicators for small registries. She said some cancers are new entities that need:

- technology for diagnosis (laboratory, imaging, etc.)
- training of professionals
- training of registrars
- Some morphological entities in ICD-O-3 do not exist in ICD-O-1 or ICD-O-2

Cancer registries normally use the following indicators in order to evaluate completeness and validity:

- %Microscopically verified cases
- %Clinical diagnosis
- % Topography: ill-defined site
- % Morphology NOS

- %Death Certificate only (DCO)
- % Autopsies
- % Of lost to follow-up

Dr. Martinez-Garcia explained that when comparing data “each tumour” or group of tumours must be studied using different approaches; taking into account age, risk factors, diagnostic resources (more or less advanced technology), treatment (new drugs, specialized centres for treatment), screening programs in the region (neuroblastoma in children) and other circumstances that may influence incidence and survival

To better understand data quality problems, the WP have explored topography and morphology NOS by registry.

She concluded saying that her WP will produce a report by October of this year (deliverable no.15). It will include a systematic analysis of the data quality indicators for the complete list of cancers layer 1 and 2 by region and the results of the checked sample of selected rare tumours records and its effects on incidence and survival rates.

3. Data quality analysis done from the WP5 (indicators)

Dr. Riccardo Capocaccia said cancer registries were selected based on data quality as low data quality can affect incidence (and prevalence) estimates. He explained the criteria to select CRs:

- sufficiently low proportion of cases with non specified morphology
- remove registries with unexpectedly low incidence of rare cancers, suggesting insufficient specificity of diagnosis
- remove specialized registries

In conclusion, incidence of all the entities was calculated both with and without the nine CRs with low sensitivity. The results did not change substantially, with only one entity changing from rare to not rare category. Therefore, none of CR was finally excluded from the analysis.

4. Cancer registry based experience on data quality

Dr. Gatta presented the results of a data review on a sample of selected rare cancers at the Lombardy Cancer Registry which covers the Varese province (about 800,000 inhabitants):

- Cases diagnosed 1995-1999, reviewed in 2008 (only cases available in the automated system were reviewed).
- Selected rare cancers were: Larynx (topography and morphology codes unspecified), adenocarcinoma of nasal cavities, eye NOS, sarcoma NOS and mesothelioma (alive three year after diagnosis)

Therefore the revision of cases available in the automated system could enhance the collection of information on stage and treatment on many cases. High Resolution studies are feasible but requires adequate funding. The EURO CARE-5 project will put emphasis on checking morphology. In conclusion, she said, it is possible to improve data quality after the positive example at the Lombardy CR.

Dr. Otto Visser (Amsterdam Cancer Registry) made a presentation on data quality of leukaemia in the Dutch CRs covering the period of diagnosis 2001-2007. They revised all the cases of CML NOS, unspecified leukaemia NOS and AML NOS. He showed the impact of the revision on survival.

He proposed for CRs to include information on grading for all cancers as this information is not available in the current RAREARE data base.

Dr Anne-Marie Bouvier of the Côte d'Or Digestive Cancer Registry explained some of the difficulties in analysing rare cancer for example: pathologists themselves are not experts in these cancers so the conclusion of their reports may often be unclear and difficulties in identifying the morphologic code corresponding to these cases. She presented some example on malignant digestive endocrine tumours and angiosarcoma of liver.

Dr. Jerzy Słowiński (The Regional Silesia Cancer Registry), Poland, talked about the quality of data in brain tumors. He said the issues that are potentially relevant to quality of epidemiological data on brain and CNS tumors are: classification, grading, ascertainment, completeness of registration, microscopic verification, reliability of histological diagnosis and differences in diagnostic capabilities between countries and regions (detection bias).

He made the following proposals:

- the unique classification and grading system (conversion to ICD-O-3 according to the Consensus Criteria)
- encourage training in diagnostic neuropathology
- putting more efforts into obtaining the material for tissue diagnosis (stereotactic brain biopsy)
- include benign tumors (consistent with EURO CARE-5 Plenary Meeting proposal)
- check the clinical data for the precise tumor site and other useful information
- collect data on diagnostic and therapeutic procedures for HR studies
- in the future, better delineation of tumor subtypes based on a molecular profile of tumor cells

Dr Gemma Gatta proposes a a short list of rare cancers for the quality control study

5. Conclusions and actions to be taken

- the present CRs agree the short list of rare cancers presented. (see appendix 1)
- to do a data quality analysis on information already available to registries (ICD-O codes,). For the list of registries that have agreed to review their data (see appendix 2)
- to check morphology codes NOS and its impact on incidence and survival
- to prepare and circulate a protocol for the data check that will be done on the rare tumour short list for the middle of June, select the cases to be checked by the CRs from the RARECARE database, send them by mid June 2009. The registries are then expected to send their revised data the end of September. The analysis will be done in October and the report on data quality for the EC for November. The protocol will be prepared by Gemma in collaboration with Carmen, Jerzy, Otto, Anne Marie and Sandra. The period of diagnosis of cases to be requested will depend on the number of cases e.g. if there are no enough cases for the year 1999 then we go in descending order to include 1998, 1997 etc until at such a time that an acceptable number of cases has been reached. A report will be produced in November 2009.
- it was suggested to invite all the CRs adhering RARECARE project to participate to the data check
- next meeting, in February 2010 (date to be decided)
- Carmen will communicate to the project leader the person (s) to do the analysis once the data is available.
- Torgil will explore the possibilities of having a seminar on rare cancers data quality during the meeting of the Association of the Nordic Cancer Registries in 2011. Sandra was also asked to do the same with the UKACR.
- Maja offered to host a session during a course she hopes to organise for her CR staff sometimes next year.

Appendix 1. Short list of rare Cancers

Mesothelioma
 Liver angiosarcoma
 Sarcomas
 Tumors of oral cavity
 CNS tumours
 Germ cell tumours
 Leukemia
 Endocrine tumours

Appendix 2: Registries that have agreed to review their data for quality improvement:

Kielce Cancer Registry
 The Regional Silesia Cancer Registry
 Estonian Cancer Registry
 National Cancer Registry of Slovenia
 Malta Cancer Registry
 Granada Cancer Registry
 Côte d'Or Digestive Cancer Registry
 Lombardy Cancer Registry
 National Cancer Registry of Ireland
 Stockholm-Gotland Regional Cancer Registry
 Geneva Cancer Registry
 Uppsala regional cancer registry
 Amsterdam Cancer Registry
 Comprehensive Cancer Centre- Groningen
 Comprehensive Cancer Centre- Twente