

Minutes of the meeting held in Milan, 27th February 2009.

Present:

Adriano Giacomini, Aidan Hutchison, Annalisa Trama, Angelo Paolo Dei Tos, Carmen Martinez-Garcia, Gemma Gatta, Greame Heron, Jan Geissler, Jan Maarten Van der Zwan, Jean Faivre, Jean Michel Lutz, Joanne Fleming, Michel Coleman, Paolo Casali, Renée Otter, Riccardo Capocaccia, Sabine Siesling, Samba Sowe, Sandra Deady, Torgil Moller

Unable to attend: Ellen Benhamou, Maja Primic-Žakelj, Markus Wartenberg, Lisa Licitra, Juan Antonio Virizuela-Echaburu, Ricardo Gonzalez-Campora

The meeting started at 9.00

Welcome, approval of the agenda and aims of the meeting

The project leader, Dr. Gemma Gatta welcomed participants and thanked them for coming. She then outlined the main aims of the meeting as follows:

- To present the preliminary results of the project: incidence, survival, prevalence and mortality on rare cancers and describe the work done after the Treviso meeting
- Agree on the short list of rare cancers
- Agree on the macro indicators that the project need to adopt
- Agree on the publication plan
- Present the project's website current situation and discuss ways of using it to improve the dissemination of the results.

The work done after the Treviso consensus meeting and the short list of rare cancers

The leader of WP 4 (Definition and list of rare cancers) Dr. Paolo Dei Tos in his presentation said in order to construct the list based on unanimity, he organised two consensus meetings, Brussels and Treviso respectively where pathologists, haematologists, clinicians and epidemiologists participated. After these meetings and a series of correspondence that followed, an agreement was reached both on the list and its rationale.

The list together with the rationale were then posted on the project's website (www.rarecare.eu) in January 2009. We wrote to twenty-four European cancer societies/organisations/associations asking them the endorsement of the list. They are all under the ECCO umbrella. We have heard from majority of them while others promised to get back to us after consulting their members.

Dr Dei Tos advanced a proposal for the short list of rare cancers, that is those with high priority for specific criteria. He advised that a rare tumour should be considered of high priority because of its relevance for primary prevention, secondary prevention/diagnosis of premalignant lesions, quality of care, diagnostic accuracy, clinical research feasibility and data quality problem in cancer registration.

Therefore, the rare cancers suggested were mesothelioma (asbestos) and angiosarcoma of the liver (vinyl chloride) for primary prevention; sarcomas for diagnostic accuracy; tumours of oral cavity for secondary prevention; CNS tumours, germ cell tumours and leukaemia for the appropriateness of treatment. For the data quality in cancer registration Dr. Jean Faivre suggested the endocrine tumours. The WP6 (data quality) will eventually add some other rare tumours. In order to conclude the activities of WP 4, mainly to widen the endorsement of the list and to utilise at the best the list of rare cancers, it was agreed to hold a plenary meeting in Brussels on the 10th of June 2009 where all the stake holders would be invited

Results on the basic/macro indicators of the RARECARE project: Incidence, survival, prevalence and mortality

Dr JM van der Zwan made a presentation on incidence and survival for rare cancer and the layout of the tables to be included in the final report on indicators. In order to received from the group attending the meeting some advices on specific issues, he made reference to a discussion held within the WP5 on the registries selection, what is interesting for report on indicators to show, how to calculate prevalence and how to show the macro indicators.

Dr Riccardo Capocaccia made a presentation on complete prevalence estimation for rare cancers and mortality rates followed by a lengthy debate as to whether or not to estimate mortality. It was at the end agreed upon to go ahead with mortality estimation for the following reasons:

Because it is

- a commitment to the European Commission on the part of the project.
- the only available indicator in most of the European countries/regions
- useful for comparison between populations

Macro indicators - relationship with rare cancer incidence and survival

Dr Sabine Siesling spoke about the macro indicators to be included in the report. The two main macro indicators she proposed for the project to adopt are:

- Gross Domestic Product (defined as the sum of the final uses of goods and services measured in purchasers' prices, less the value of imports of goods and services, or the sum of primary incomes distributed by resident producer units).
- Total National Expenditure on Health (The sum of expenditure on health related activities, listed on the OECD website (www.oecd.org), through application of medical, paramedical, and nursing knowledge and technology.

They will be:

- included in the survival tables
- used for High Resolution studies (future)
- used to search for country indicators using the Guidelines International Network (GIN) available in many countries (Dr Renée Otter's suggestion)

A suggestion was made to compare survival of rare cancers between low and high income countries using the "EUROCARE model".

Dissemination of the results: publication plan and web site

After the proposal by Dr Gemma Gatta and Ian Kunkler discussed at the Edinburgh meeting, the participants agree that the project management will prepare a publication plan to be presented during the Brussels plenary meeting (10/06/09). Invitation will then be extended to all the registries that contributed data to the project and researchers involved to choose to author or co-author a given paper. Prof. Michel Coleman suggested to proceed as for the EURO CARE project, for the definition of authors and content of the papers.

The project's website and the dissemination of the results falls under the responsibilities of WP 2 represented at the meeting by two web technicians. One of them (Graeme Heron) made a presentation showing its current state and put forward suggestions on how he think it could be improved. He proposed to split the website into 3 areas

- *Public Information:* under this section, an area will be created to host downloadable PowerPoint files of all future presentations, post minutes and agendas of public meetings, colleagues not able to attend can view the PowerPoint presentations and get an idea of what was discussed, record and film future meetings (where deemed necessary) and the audio merged with the presenters PowerPoint.
- *Dissemination of Results:* Gemma proposed to use existing GLOBOCAN (2002) Tools as it compatible with the RARECARE data. She will speak to J. Ferlay, asking him permission to utilise it for the RARECARE project.
- *SharePoint:* This requires registration with the University of Edinburgh (host of the website) at the indication of the project's management. It serves as a central repository for all documents, it enables you to discuss documents in the form of a forum and its both version control and editable

He informed the meeting that since the rare cancers list was posted on the website in January, its visitors have doubled. He was asked add a link to the WHO blue book for possible use by clinicians

It was agreed to provide links on voluntary based translation into some European languages of some of the pages e.g. the home page and aims and objectives of the project. The number of languages would obviously depend on the number of volunteers we have for each language.

Other issues

The European Organisation for Research and Treatment of Cancer (EORTC) was one of the twenty four organisations we sent the list of rare cancers with its rationale asking for their endorsement provided that they agree with us. During its Board meeting on the 30th of January 2009, two Board members expressed interest in collaborating with the RARECARE project, that they found the initiatives very interesting. As their main area of activity is on conducting international clinical trials on rare diseases, it was agreed that we could collaborate with them for the epidemiologic competence.

As the 2nd Interim Report to the EC would be due by mid May, WP leaders were reminded to:

Send their cost statements covering the period 01/04/08 to 31/03/09.

For the cost statement, Samba was asked to prepare an excel file and send it to the WP leaders so that they just fill in the information required.