

RARECARE project
WP5 meeting on how to proceed the project towards D13
Utrecht, 7th November, 2008
Minutes

List of participants: Gemma Gatta, Riccardo Capocaccia, Renée Otter, Sabine Siesling, Michael Schaapveld, Jan Maarten Van der Zwan

Unable to attend: Carmen Martinez, Angelo P Dei Tos, Sandra Deady, Lisa Licitra. Paolo Casali, Roberta de Angelis.

After the approval of the agenda, an introduction of the aims for this meeting was given by the work package leader Renée Otter, focussing on the major steps that have to be taken for having a satisfying report in March 2009.

The major points discussed during this meeting towards deliverable 13 (D13) were:

- What will and should be the content of the report (D13)
- What indicators will be used for the report (D13)
- A time schedule and work distribution plan reaching the set deadline for D13

After this introduction Gemma Gatta announced that Laura Ciccolallo is no longer working for instituto tumori, Milan and thereby also left the RARECARE project.

Presentation:

1. Gemma Gatta gave a presentation on the RARE tumours list, developed by WP4.
In this presentation Gemma Gatta showed the RARE tumours list which WP4 proposes and discussed the difficulties and the lay out of the list as it is now.
A short discussion followed on why there has been chosen for this way of presenting the data within the RARE tumours list.
2. Gemma Gatta announced an online questionnaire, which will be put on the internet. An invitation for answering this questionnaire will be send to experts in different cancer fields, to gain suggestions towards improving the list as it is now. Also an announcement was made that a new statistician will be attracted in Rome to support this project.
3. Riccardo Capocaccia proposed a standard lay out for the tables, to be presented in the final report (D13). This proposal was accepted.

Discussion:

1. The content of the report has been discussed and had the following outcome;

- An introduction and a chapter on methodology will be a part of the final report (D13).
- A first list of incidence and prevalence of all the red and blue layers within the full RARE tumours list will be produced.
- A second list of all indicators will be produced for only the RARE tumours within the RARE tumours list; this will result in an overview of one entity per page.

The indicators per rare entity are:

-Incidence	-Survival
-Prevalence	-Mortality
-EU region	
-Age	
-Sex	

Macro indicators	:	-Socio economical factors (TEH and GNP)
		-CT scanners per 100.000 pop.

Crude rates will be used for "health care pressure" relevance. Age standardisation will be calculated for comparison.

2. Relation with other Working Packages has been discussed and had the following outcome;

WP4; the RARE cancer list of WP 4 will be used to select the entities to calculate. As WP4 is still improving their list, changes on the list should be communicated with WP 5. Especially WP 5 is awaiting the results of the questionnaire initiated by WP4.

WP6; the qualitative good registries have to be selected by WP6. Pending on their decision, per entity, the selection will be used for calculation of indicators for D13.

Quality needs to be checked on the following 3 aspects;

1. Registries that only have specialized data.
2. What proportion of entities are registered as "Otherwise specified" per registry
3. Are special entities coded correctly, e.g. GIST cells?

3. A time schedule and work distribution has been discussed and had the following outcome;

-Preparation work files for SEERstat	→ 1 st December, Jan Maarten / Michael Schaapveld, Gemma Gatta will provide the final WP4 list the coming week.
-Final list of registries to in- / exclude per entity	→ 15 th December, Gemma Gatta
-List one → (Complete) Prevalence	→ 31 st January, Riccardo Capocaccia
→ Incidence	→ 31 st January, Jan Maarten van der Zwan / Michael Schaapveld
-List two → (Complete) Prevalence	→ 20 th February, Riccardo Capocaccia
→ All other indicators	→ 20 th February, Jan Maarten van der Zwan / Michael Schaapveld
→ Collect the Macro indicators	→ 20 th February, Sabine Siesling
-Chapters on introduction and methodology	→ 20 th February, Gemma Gatta
-Feedback outcome questionnaire	→ 20 th February, Gemma Gatta

4. A new joint meeting of WP4,5,6 has to be organized;

The meeting will be arranged by Gemma Gatta in the last week of February or in the first week of March. In case the meeting will be in the first week of March than Gemma Gatta will possibly ask the EU commission permission for delay of the report (D13).

The agenda of this joint meeting will contain the following elements;

1. Present results to other WP's
2. experiences of WP6
3. Start summary with high lights
4. Publication plan – topic decision
5. Feedback to WHO about blue books with this RARE tumour list.
6. Time frame final tables and conclusions.

Last questions

Gemma;

1. Gemma asked Renée Otter if she has any questions that she would see in the online questionnaire about the RARE tumours list (WP4 proposed).

Answer by Renée Otter: Yes, namely;

- Are these entities you recognise?
- Will you use this list for clinical decision making (diagnosis / treatment) for concentration of tasks within the country.
- Option: include EU memberships / ministry of health as participant for filling the questionnaire, than ask; Will you use this list for capacity building?

2. It is not possible for me to attend all meetings / congresses to represent the RARECARE project, would it be possible for others to go to interesting meetings / congresses. If someone goes to represent RARECARE than Gemma her name will always be named on the Poster of during the presentation, Gemma will always be informed.

Jan Maarten;

1. Now Laura is not working for the RARECARE project anymore, while she was responsible for the link between the working packages and the website, who will now be responsible for this link? And who is now checking the information on this site, some things will be out dated.

Gemma Gatta: That now will be Samba Sowe. He will also check the information on the site, if that is still up to date.

Note made by Michael: This is important because now more people will visit the site for filling the online questionnaire. It would be strange if those people see a site under construction with old information.

2. What will be the product of WP 2, which has to deliver a publication plan, do we have to communicate with them about our needs for this plan?

Gemma Gatta / Renée Otter: Of course they need to know what our plans are for further publication, they can't make a plan on their own.

Suggestion by Renée Otter: Try to invite them too for the joint meeting in February, otherwise we have to send them our points for this publication plan

Closing

Renée Otter closed the meeting with a small gift and wishes all participants a safe journey home.