Minutes of the Dissemination Workpackage RARECARE
13th February 2009
Breast Unit Seminar Room, Western General Hospital

In attendance:
Riccardo Cappocaccia
Gemma Gatta
Graeme Heron
Ian Kunkler
David Perry

Apologies:
Samba Sowe

Website development

1. **Issues relating to website**

(i) It was recommended that results of the project and internal minutes/ discussion of RARECARE/documents were confined to the members only part of the site.
(ii) List of rare cancers, selected slides about the project (GG to select) and publication plan should be on the public access part of the site.
(iii) No subdivision of the public access part of the site was recommended between general public and cancer professionals.
(iv) Hosting discussion site in which members of the public could exchange views about rare cancers was felt to be problematic since we not have the resources to vet content or to response to questions from individuals.
(v) Linkage to other cancer patient focused websites which already host such discussions for patients/general public seems more appropriate (eg European Breast Cancer Coalition.
(vi) DP indicated that there had been some limited use of the Sharepoint software between RARECARE members. This has some advantages over traditional email to sharing updated versions of files. GG indicated that some members may prefer to continue to use email. DP would liaise with Samba Sowe to send out reminder about Sharepoint and how to use it. Members could continue to use email if they wished. GG reported that some members had experienced difficulties in logging in. **ACTION: DP/SS**
(vii) GG indicated that it would be necessary to update the website every 2 or 4 weeks.
(viii) DP felt that the adobe pdf format was the most inflexible way of sharing data since the data could not to be changed into other formats.
(ix) DP recommended that RARECARE data/slides downloaded from the website should have embedded and fixed RARECARE provenance. GG agreed and powerpoint presentations at recent RARECARE meetings had carried RARECARE logo.

2. **Techniques for enhancing presentation of information on the website**

(i) DP indicated that there were a number of tools available to present data in a more user friendly and interesting format. These included visualization tools, data mining techniques, webcasts of RARECARE meetings.
(ii) It was agreed that DP and GH would, subject to the agreement of the RARECARE steering committee, film some of the presentations at the Milan meeting of 27.2.09 and in

the update of the dissemination WP explain what techniques could be used to enhance visibility of RARECARE project activity on the website.
GG agreed to notify steering committee members of this proposal and identify individuals who would agreeable to being filmed. **ACTION: GG/DP**

(iii) Analysis of survival
RC demonstrated the data on survival that would need to go on the website. RC agreed to send the file to DP to explore what techniques might be appropriate to maximize its impact on the website. IK felt that GLOBOCAN had very useful display of maps of cancer incidence and data displays that might be applicable to RARECARE.

GG suggested exploring collaboration with GLOBOCAN and START project to access successful templates for data display. GG agreed to contact GLOBOCAN and START representatives. **ACTION: GG**

3. Translation of the website content into other languages

(i) The deliverables for the dissemination WP included translation into other European languages. DP indicated that this would be feasible if the navigation system of the website remained in English alone but that some fixed content which had been translated was available and flagged.
(ii) DP indicated that translating the whole of the website into other European languages would be beyond the resources available for site maintenance. Editing changing informal into multiple languages would be difficult and time consuming.
(iii) The flagging of core content in different languages should only be done once the same minimum amount of text in a particular language had been approved for loading on to the side. This was to avoid varying amounts of translated material in different languages making the website look patchy.
(iv) It was agreed that all the current fixed content with the exception of the definitive list and the rationale for the list should be translated into Italian, French, Dutch, German, Polish and Slovenian at the minimum. The navigation system on the website would remain in English. GG agreed to identify RARECARE members to help with the translations. **ACTION: GG**
(v) Glossary of terms. DP felt a glossary of terms was need for the lay public to explain incidence, prevalence etc. GG and RC agreed to write this. **ACTION: GG, RC**

4. Next steps for website development

DP felt the following issues needed to be addressed**:**

(i) Putting powerpoint presentations online
(ii) Filming presentations at Milan 27 Feb meeting
(iii) Developing prototypes of data templates accessible online
(iv) Embedding provenance of RARECARE data
(v) Ensuring work on website kept within resources available
(vi) Develop action plan for next 6-12 months for website development and management

It was agreed that an action plan would be drawn up at the next meeting of the Dissemination WP on June 17th, 2009 in Milan. GG would arrange input from RARECARE steering committee, GLOBOCAN, START and patient representatives. **ACTION: GG**

Comments from European Organisations on draft list of rare cancers

(i) The draft list of rare cancers had been circulated to European cancer societies for comment. Affirmative responses had been received from the EORTC, ESSO, European Society of Neurooncology. Other responses were still awaited including BIG. IK would contact BIG

ACTION: IK

(ii) IK felt that the interest of the EORTC in supporting a further funding initiative to support research on rare cancers was particularly encouraging. IK recommended that we responded very positively seeking clarification from the EORTC on how this cooperation might be most effectively organized to maximize the impact of RARECARE. A joint meeting might be held with the EORTC and its cancer site specific research groups representatives to study the RARECARE finding, their interpretation and the priorities for new clinical and translational research in rare cancers in Europe. IK would draft response to EORTC.

ACTION: IK

Publication policy

(i) *IK proposed the following principles for publication*:

A writing committee will be established by the workpackage leaders responsible for preparing publications arising from the RARECARE project for submission to peer reviewed journals.

Names of participating groups that have contributed to RARECARE will be clearly stated in publications reporting the results of RARECARE.

Names of investigators who have contributed data to RARECARE will be named in an appendix in articles submitted for publication.

Articles reporting the results of RARECARE will be circulated, where appropriate, by the writing committee to representatives of collaborating organizations for comment prior to submission.

An overview on the publications arising from the trial will be maintained by the RARECARE steering committee who will be the arbiters in the event of any disagreement relating to publications

GG would discuss these proposals with the steering committee **ACTION: GG**

(ii) *Choice of journals for submission of articles*

It was felt that Lancet Oncology with its high impact factor (>12) would be the preferred choice for publications on treatable rare cancers where differences in outcomes had been identified. Other journals for important papers where the impact might be lower included British Journal of Cancer, European Journal of Cancer, Annals of Oncology.

(iii) *Topics for articles*

a. IK suggested dividing papers which provided a survival analysis by anatomical site (Head and Neck, Thorax, Gynaecological (including breast), Urinary, Haematological, Skin). GG suggested specific papers on sarcomas and neuroendocrine with no division between paediatric and adults cancer but a paper included on embronal tumours.

b. GG suggested a general paper on the list and its justification and cancer incidence and a paper on preventable cancers (eg mesothelioma and angiosarcoma of the liver. IK felt that difference in incidence and survival for these cancers would have implications for public policy.

c. IK emphasized importance of identifying lead authors for papers once the topics had been decided and ensuring cancer site specific clinician input into the writing so that expertise in interpretation of the results was available.

(iv) Submissions of abstracts to meetings

It had been decided not to submit an abstract to ASCO this year.

GG favoured invited oral presentations. IK indicated that these were desirable but different to elicit. The traditional submission route for abstracts seemed the most practical with the hope that a high impact abstract might command a plenary presentation.

ESTRO, ASTRO, ECCO/ESMO, ESSO, ESNO were possible meetings as well as the November international meeting on cancer control organized by Andrea Micheli in Italy.

Samba Sowe had developed a list of possible meeting to which abstracts might be submitted.

IK suggested GG wrote to the RARECARE members for suggestion meetings and abstract deadlines. **ACTION: IK**

Finance

GG indicated that no claim against budget had been made for Year I and this was causing a significant problem for the RARECARE administration and its relation to the Commission. This might compromise the release of budget for year 2. IK explained that there had been a considerable delay in the University administration issuing a grant number to RARECARE for which he apologised. This had now been done. IK would be contacting Ann Reynolds in the University to indicate the urgency of resolving the situation. **ACTION: IK**