



MEETING of the PROCARE **STEERING GROUP**

4 May 2009

Place: RIZIV/INAMI, Tervurenlaan 211, Brussels, 8th floor **Jan Van Eyck room**.

Minutes of the Steering Group

Invited: Cabooter, Melange, Pattyn, Buset, Rahier, Danse, Op de Beeck, Smeets, Scalliet, Spaas, Haustermans, Bertrand, Burnon, Claeys, De Coninck, Duinslaeger, Kartheuser, Penninckx, Van de Stadt, Vaneerdeweg, Haeck, Mansvelt, Demetter, Jouret, Sempoux, Bleiberg, Humblet, Laurent, Peeters, Polus, Van Cutsem, Van Laethem, Van Eycken, Dercq, Thijs A.

Invited: Vos Karen (FBCR), Dr Van Gijn W (NL).

Apologies: Sempoux, Van Laethem, Spaas, Mansvelt, Laurent

Present: Bertrand, Burnon, Danse, De Coninck, Demetter, Duinslaeger, Haustermans, Jouret, Kartheuser, Penninckx, Scalliet, Van Cutsem, Van Eycken, Thijs A.

Invited: Vos Karen (FBCR), Dr Van Gijn W (NL).

Start 20.10

1. Minutes 28 October 2008. (re)approved (cfr www.registreducancer.org)

2. Guidelines: need for update in 2010.

Decision: Suggestions to be sent in the second half of 2009 to Penninckx who will edit an updated version (with help of professionals for lay out; cfr. infra)

3. PROCARE database

3.a. Chemotherapy section of the data entry set: updated (pre-circulated in attachment of the agenda). **Decision** : approved

3.b. Evolution of entries (EVE): The Group is pleased with 2340 patients submitted from 70 hospitals (49 Dutch, 21 French).

3.b.1. **Decision:** 'reminder' to be sent to 44 non-participating centers (13 Dutch, 31 French), also asking why, with summary of GL, QI, RT atlas, APO atlas to be prepared by Penninckx F; to be sent by EVE/FBCR.

3.b.2. **Decision:** Mail to be sent to all participating colleagues, in particular those who did not submit patients in recent months (also asking why), with summary of GL, QI, RT atlas, APO atlas to be prepared by Penninckx F; to be sent by EVE/FBCR.

3.c. Web application for data entry. Mrs Vos K and EVE gave a demonstration. The application will be tested within 1 month, to be released thereafter.

3.d. Participation in the European Prospective Colorectal Audit (Dr Willem Van Gijn, NL, invited): In fact, Dr Van Gijn aims to finish a PhD thesis in Leiden (Prof

van de Velde C) in 2010. Dr Van Gijn stated that PROCARE will remain the owner of the data.

Decision: PROCARE agrees to collaborate in principle (awaiting further information that will be circulated to the Steering Group by Penninckx F). It should be unequivocal that PROCARE data can and will not be used/exploited for 'any aim'. In fact, the data should be deleted at the end of the study by Dr Van Gijn. Dr Van Gijn has to send the aim, required data etc.

3.e. Collaboration in a 7th Frame EU multinational project. Pahlman L sent an email that was circulated to the Steering Group including in attachment the minutes of a meeting in Poland (Katowice): "Enclosed you find a report from the meeting we had in Katowice. We were discussing how to evaluate the knowledge and the standard of colorectal cancer surgery in Europe. Since we know that Belgium has a similar register to some other countries we would like to include Belgium in the EU-application within the 7th Framework Programme. The hard work will be done by Pawel Mroczkowski (Poland) and Jason Smith (England) together with me (Sweden). However, we want to have you (i.e. Belgium) involved in this application, if OK. Please let me know as soon as possible whether this is something you can consider."

Decision: Agreement to participate 'in principle' awaiting further detailed information (duties, deadlines, Financial support). Penninckx informed Pahlman by mail on May 5th 2009.

4. TME candidate TME trainers and TME training (E Van Eycken)

4.a. TME trainers and candidate trainers: Recently, 3 new TME trainers fulfilled the requirements, for an actual total of 18 trainers (14 Dutch, 4 French). The pathology evaluations of candidate TME trainers is coming to its end with some cases of 1 (max. 4) candidates to be reviewed.

Decision: The pathology review board will start to evaluate TME specimen from any participating at random, as planned (Jouret, Van Eycken).

4.b. TME training : very limited 'interest' until now (E Van Eycken). Since August 2008, 3 surgeons asked for TME training (2 were assisted at 3 cases, 1 at 2 cases). After the presentation on PROCARE at the BSW May 1st (FP), no very relevant feedback/suggestions were received.

Decision: mail to all participating surgeons highlighting the possibility and modalities of TME training. This mail should also include the updated data entry set and may announce the web application. A plan for potential re-allocation of the financial support for TME training is made (cfr. infra).

4.c. feedback to submitting pathologists (AJ): a form had been prepared by Mara (former datamanger) and Jouret but was not finalised.

Decision: Penninckx F will do so in collaboration with Jouret and Van Eycken. A copy of the pathology review should and will not be sent to the pathologists; instead a summary (with more detailed info if requested i.e. why not evaluable, will be sent for each submitted case.

5. Radiology and PACS (E Danse). The PACS made by Ebit is installed and is being tested. It works well, but needs some adaptations (costs 8000 €). Radiology reviewers have to be remunerated (cfr. infra).

6. Radiotherapy and Platform for Communication and Evaluation (P Scalliet). PACS is not an adequate terminology and should be replaced by Platform for Communication and Evaluation (PCE). Cfr. infra.

7. PROCARE feedback and benchmarking (F Penninckx)

7.a. Feedback 2008 : no comments and remarks. The lay out can be improved.

7.b. Planning Feedback 2009 summer and winter (2x/yr) ? It seems that a feedback report can be finalised by the end of the summer. A second feedback seems to be very difficult to realize. Moreover, Dr Mertens CI asked to stop her activity at the FBCR for familial reasons.

7.c. Risk adjustment for case-mix and low number of patients. A proposal for project at the KCE was pre-circulated in attachment of the agenda. This topic is considered to be very important and warranted.

Decision : Approved. In case of acceptance, a delegation of clinical experts from PROCARE, representing all disciplines, will be asked to participate actively. The data from the PROCARE database used for study should be strictly anonymised, according to the PROCARE policy.

8. Report of the financial committee (F Penninckx). **Decisions** made:

8. 1. RIZIV/INAMI support: 660 442 € available (status per 26th April 2009)

The 275 500 € planned for TME training will (potentially/probably) not be used. If 20 would ask for, about 220 000 € could (have to) be re-allocated to the following aspects of the project.

1. consulting statistician (0.5 FTE equivalent) from beginning 2011 till mid 2012 (end of project): 60 000 €.

2. supplementary TME evaluations by the pathology review board (if feasible). Number to be defined. Jouret et al work a-on a proposal and discuss the feasibility with the full board of the Digestive Pathology Club. If a 'go' is possible, Penninckx checks which training centers do not participate yet in the project and writes a letter to motivate and stimulate them in order to start participation, including TME evaluation.

Definitive decisions will be made at the next meeting in the autumn 2009.

8.2. Datamanagers FBCR. As planned 100 000 € will be transferred to the FBCR for the 3rd year payment of 2 datamanagers at the FBCR.

8.3. Participants at the Steering Group meeting will receive 100 € per meeting i.e. 50 €/hour. Penninckx to make a list based on the minutes starting per July 2007.

8.4. Publication on high quality paper and with appropriate (professional) lay out of a summary of the guidelines, quality indicators, data entry set with definitions and feedback data. To be prepared for the next feedback. Costs covered by budget.

8.5. PACS for radiology (CT/MRI staging). The cost for training sessions (workshops for radiologists) in which about 9 experts will collaborate is estimated at (9 x 250=) 2 500 €.

Remuneration for the reviewers (first as well as second, if required) fixed at 30 €/patient.

8.6. Platform for Communication and Evaluation fro radiotherapy.

The Federation against Cancer will give a grant of 100 000 € (Scaillet P).

Other sources for financial support could come from the College of Radiotherapy or from the RIZIV/INAMI. Scaillet P will write a letter to Dercq JP with a short review of the status and a thorough motivation of the costs. In very brief, the high cost is related to the fact that not a PACS but a “PCE” is required for radiotherapy reviews and training.

9. Presentations and publications

9.a. Leonard: manuscript on “Analysis of factors predicting TME quality”: in pre-final stage (statistician). **Decision:** No names of surgeons/pathologists involved will be mentioned as it had been decided previously not to ‘publish’ or make public the names of TME trainers.

9.b. Kartheuser A et al: chapter AFC book on rectal cancer : submitted. Agreed.

9.c. Kartheuser A: presentation on PROCARE at meeting of Santhea and in Chimay. Agreed. The presentation will be put on the PROCARE website.

Santhea est une association professionnelle et patronale qui a pour mission de défendre et promouvoir les intérêts des établissements et des services de soins non-lucratifs du secteur privé non-confessionnel et du secteur public, situés en Wallonie et à Bruxelles (Belgique). Il s’agit de la première association francophone du secteur et d’un interlocuteur de référence, avec la représentation de près de 48% des établissements de soins des deux régions. Elle est à ce titre la 1^{ère} association professionnelle francophone et la 2^{ème} belge. Elle représente tous les hôpitaux publics de Wallonie et de Bruxelles.

9.d. Achievements and difficulties of PROCARE after 2.5 years (Colorectal Disease)? After next feedback (with more data) ? No candidate(s) yet.

9.e. Dr Mertens (FBCR) was planning a publication on the QCI in rectal cancer management . In fact, a ‘summary’ of the second report made in collaboration with KCE. However, Dr Mertens will leave the FBCR by the end of the year because of familial reasons. Candidates to take over this still interesting topic? Not yet.

10. Newsletter to be elaborated by E Van Eycken. The last Newsletter dates from July 2008, but was followed by the feedback. Active collaboration from all disciplines involved is warranted and highly appreciated.

11. No other business

12. Next meeting to be planned in October 2009.

Adjourn 22.15