



AGENDA of the PROCARE **STEERING GROUP**

Tuesday 20 April 2010

Place: RIZIV/INAMI, Tervurenlaan 211, Brussels, 8<sup>th</sup> floor **room P Breughel** (entrance via car parking St Michielscollegestraat 69).

**Start 19.30 for the Steering Group**

**Agenda of the Steering Group**

Present: Bertrand, Burnon, Danse, Demetter, Demey, Duinslaeger, Jouret, Kartheuser, Laurent, Mansvelt, Pattyn, Penninckx, Vaneerdeweg, Van Eycken, Thijs A.

Invited ad hoc: Goetghebeur Els (professor at the Dept. Applied Mathematics and Computer Science, UGent)

Apologies: De Coninck, Haeck, Haustermans, Peeters, Scalliet, Sempoux (abroad), Spaas, Van Cutsem, Van de Stadt

**1. Welcome**

Dr Wim Demey joins the Steering Group, replacing Bleiberg H on behalf of BSMO.

**2. KCE project on risk and volume adjusted analysis for benchmarking and feedback**

**2.a. Some pre-remarks (FP):**

- PROCARE decided to ask support for risk/volume adjusted analysis for benchmarking and feedback
- the KCE accepted the plan for project submitted by I-Biostat (group of statisticians from KUL and UCL) in collaboration with PROCARE on 29/10/2009.  
Candidate-clinicians delegated by PROCARE were/are:
  - oncology: Van Cutsem, Van Laethem, Laurent, Vandeneynde (UCL)
  - radiotherapy: Haustermans, Scalliet
  - pathology: Demetter, Nagy, Jouret
  - BPSA: Vindevoghel Koen (Waregem), Molle Gaetan (Jolimont)
  - Surgery: Ceelen, Van de Stadt, Kartheuser
  - Radiology: Danse
  - PROCARE database: Penninckx, Van Eycken
- the KCE on 9 March 2010 decided to engage a group of statisticians and clinicians from UGent et al (cfr. precirculated ppt from the UGent group attached to the mail of 22/03/2010, with permission).
- FP informed the Steering Group repeatedly (last time 20/3/2010 as well as on 22/03). Remarks made by members of the Steering Group as well as some others concerned colleagues were summarized in an attachment to the mail of 31/03/2010 (summary made by FP).

**2.b. Presentation of KCE project by Prof Goetghebeur Els, followed by Q&A (cfr 2 attached documents to the mail of 31/03/2010).**

### **2.c. Discussion and decisions:**

1. PROCARE has guaranteed confidentiality to all participating teams. PROCARE data cannot be given to a third party neglecting the original aims and conditions. Data can only be provided to any third party under stringent conditions with a confidentiality and privacy guarantee. Therefore, data can not be given through the KCE. Data may be given to a research group under strict conditions (e.g. as a formal contract: cfr attachment to mail of 18/04/2010).

2. PROCARE has no preference related to the origin or location of a statistical research or consulting group. However, the PROCARE nature and aims should be respected and the major goal should be the search for the methodology required for risk and volume adjusted analysis for benchmarking and feedback.

3. It is highlighted that PROCARE is an educational project aiming to improve quality in all participating centers. To 'name and shame' low-outliers does not fit with the nature and spirit of the PROCARE project.

4. The chairman is asked to make contact with Dr Mertens R (director KCE) in order to check the intentions of the KCE. The following should be guaranteed:

- no 'name and shame' of low-outliers strategy or aim (if this would be the case, PROCARE will not participate in this specific project)
- a purely scientific and educational approach should be followed. No 'political' aspects. This does not exclude that in a later stage risk adjusted analysis and benchmarking based on PROCARE data and administrative data will be compared (aiming to evaluate whether a detailed specific database is required to assure quality of care).
- all clinical PROCARE delegates (cfr supra) should be part of the project from the start till the end. They cover and guarantee expertise in all domains of the management of rectal cancer
- the results of all parts of the project should be discussed with and approved by the clinical PROCARE delegates
- in order to guarantee scientific and clinical objectivity and in order to respect the nature and aims of the PROCARE project it is essential that the PROCARE Steering Group should approve the prefinal results and text before it will be submitted to the KCE.
- PROCARE has to be an integral part of the research group and of the KCE contract
- an external expert should be indicated by PROCARE and proposed to the KCE for review of the final report, after internal validation.

The chairman (FP) contacted Dr Mertens. A positive spirit of collaboration on behalf of the KCE was evident. Thus, Dr Mertens was kindly invited to an extraordinary PROCARE Steering Group meeting. He accepted immediately. The meeting is planned on 12<sup>th</sup> May 2010 in the RIZIV/INAMI.

**3. Minutes 4 November 2009.** Have been approved (cfr [www.registreducancer.org](http://www.registreducancer.org) under PROCARE, publications, minutes).

### **4. PROCARE database**

- a. new data entry set on website and mailed to all participants. In use since January 1<sup>st</sup> 2010.
- b. web application (EVE). The contract between FBCR and PROCARE has to be adapted. **To do.**
- c. evolution of participation and patient entries

Taking into account recent hospital fusions 77/111 (69%) hospitals participate.  
The aim is that within 1 year >75% of the hospitals will participate.  
3215 patient data sets in database. Mails sent in 11/2009 to all participating colleagues who submitted no more cases since 1/2009.

**5. PROCARE feedback:** (FP)

- a. the second feedback was given to all participating teams in 12/2009 after preview and approval by the Steering Group (via mail). Analyses were made by Dr Mertens Claire and Koen Beirens at the FBCR after major efforts to update and 'clean' the database (FP + FBCR). These documents are available on the website. More QCI were included as well as other data. Feedback on DFS and LRR at 2 yrs as well as on adjuvant treatment could not be given due to limited follow-up data. A specific effort to obtain relevant data on adjuvant treatment, local and/or distant recurrence was done via mail to all participating teams.
- b. Feedback in 2010: data on QCI only will be reported in June 2010 and the full set in December 2010, including risk and volume adjustment (if possible).

**6. TME training** (delegates of BSCRS and BPSA and E Van Eycken)

- a. TME training : 3 surgeons have been trained, 2 are in training and 2 planned training.
- b. A reminder about the possibility of TME training was sent together with above mentioned mails.

It is evident and confirmed that side by side TME training will not reach the 'volume' that had been anticipated based on 'intentions' at the workshops in 2005. Related costs have been re-allocated (to be confirmed by Verzekeringscomite – RIZIV).

**7. TME review Pathology Board**

The pathology board centrally reviewed 115 TME specimens at random. This process will be continued.

The datamanager registers the (non)availability of adequate/good material for review.

The pathology board will produce an evaluation form per specimen; after review by delegates from the BSCRS that form will be sent to the pathologist and surgeon by the datamanager.

The TME 'cookbook' has been updated (AJ)

**8. PROCARE RX** (ED)

The platform has been tested by 6/9 invited radiologist-reviewers. PROCARE RX will be launched on 1<sup>st</sup> May 2010.

**9. Radiotherapy and PCE.**

Concernant l'installation de plateformes AQUILAB, le projet termine ses tests entre 4 hôpitaux (St Luc, Gasthuisberg, Namur et Middelheim) avec succès. Nous ouvrons totalement le réseau à partir du 3 mai. Donc ça marche très bien.

Toute aide financière serait la bienvenue, si les budgets non dépensés pouvaient être re-dirigés vers la radiothérapie. Je sais que nous avons eu un avis négatif de l'INAMI en 2009, mais nous voulons repenser la question. Est-il possible de "récupérer" des sommes non utilisées dans d'autres parties du projet?

Aquilab installaties voor PROCARE

SITES	NOM CONTACT	DATE INSTALLATION
UCL St Luc Bruxelles	Maxime Coevoet	19/11/2009
UZ Gasthuisberg Leuven	Jan Verstraete	20/11/2009
Clinique St Elisabeth Namur	François Sergent	3/02/2010
ZNA Middelheim Antwerpen	Eric Messens	8/12/2009
CH Jolimont Lobbes Haine St Paul	Carine mitine	
Hôpitaux St Joseph Gilly	Françoise Gilsoul	
CHU Liège		
RHMS Baudour	Joelle Fraikin	
CHU Charleroi		
CH Peltzer Verviers	Yassinne Boukour	5/11/2009
AZ Sint Jan Brugge	Geertrui Demeester/Dr Bols	
Institut Jules Bordet Bruxelles		
St Elisabethziekenhuis Turnhout	Jean Meykens	23/02/2010
Algemeen Sint Maarten Duffel	Philippe Spaas	20/04/2010
VUB Bruxelles	Guy Storme	
AZ Sint-Augustinus Wilrijk	Philippe Huget	
Virga Jesse Ziekenhuis Hasselt	Paul Bulens	
Centre Cogniaux-Dancot Bruxelles	Philippe Warnier	
Kliniek Sint-Jan Bruxelles	Sylvie Beauvois/Dr Gérard	1/04/2010
AZ Goeninge Kortrijk	Antoon Lambrecht	
OLV Ziekenhuis Aalst	Luc Verbeke	23/03/2010
Europa-Ziekenhuis Bruxelles	Marina Debecker	
Universitair Ziekenhuis Gent	Wilfried De Neve/Pr Tom Bottleberg	
AZ Sint Lucas Gent	Franck Bouttens/Dr Duthois	
Heilig Hartziekenhuis Roeselare	Lorenzo Staelens	23/04/2010

**10. Guidelines (and Quality of Care Indicators):** an update is appropriate. PROCARE guidelines were published in 2007. Clinically relevant advances have been made in some aspects of rectal cancer management. Planning: **to be organized in 2010.**

**11. EU 7<sup>th</sup> Framework** (FP). The proposal of a European ‘consortium’ including PROCARE has not been retained.

### **12. Presentations and publications**

**Leonard D** (mail dd 21/3): asks permission to write a short article (2 pages) about the project (purpose, design and aims) for the bi-annual information periodic (not peer reviewed) of the french speaking stoma nurse association. Leonard will clearly state “on behalf of the PROCARE steering group” and submit his final draft to the steering group prior to submission for publication. **Decision: approved**

**Mroczkowski P** mail dd 31 March 2010 (cfr attachment to mail of 31/03/2010): “I would like to present this [German-Polish] project and these data in an international context... I would like to use description of your projects and I would like to compare our data with your data...”. **Decision: approved**

**Eurecca** (European registration of cancer care) mail dd 31st March 2010 (cfr attachment to mail of 31/03/2010):

“Our proposal is to organize:

- 1) A biannual forum (meeting of 2 days) to update the treatment consensus and share evidences from ongoing population based registries.
- 2) Standing working group(s) to finalise the definition and dissemination of QA standards in collaboration with international and national societies, and cooperative groups. Individuals, Societies and Working Groups which are interested in working together in this direction are requested to confirm their availability to Willem van Gijn (W.van\_Gijn@lumc.nl). Thereafter, we will try to organize a EURECCA Launch Committee to arrive with a formal proposal of founding a EURECCA Consortium at the Bordeaux ESSO meeting.” **Decision: approved**

**Burnon D:** presentation of PROCARE at the Congrès national de la Société Libanaise de Chirurgie Générale, BEYROUTH 10-11 juin 2010 qui se fait conjointement avec la Société Royale Belge de Chirurgie. **Decision: approved**

**Pro memoria:**

- a. Leonard: manuscript on “Analysis of factors predicting TME quality” accepted for publication in Annals of Surgery (‘in press’)
- b. Nagtegaal, Quirke, et al. 'Evidence-based medicine: the time has come to set standards for staging' submitted to Journal of Pathology. Accepted for publication.
- c. plans of pathologists
  1. un écrit par A Hoorens( VUB) dans le Belgian Medical Oncology
  1. un écrit par Jouret-Mourin en collaboration avec P Demetter (ULB). A ce propos, nous allons rencontrer Liesbeth le 24 aout (2009) à 14h au registre . L'article portera sur le résultat de la relecture des lames de Procure "versant anatomopathologie"
  1. on peritumoral inflammation and prediction of tumor response to CRT (Pattyn/Libbrecht UGent & Geboes/Sagaert KUL et al). PROCARE has no resources for research. Limited uni- and multivariate analysis on well structured data can be performed by Koen Beirens and colleagues at the FBCR. However, they should not take too much time and no specific reimbursement will be paid.
- d. FP (who is candidate to co-write?): achievements and difficulties of PROCARE after 3 years (Colorectal Disease) ?

**13. Newsletter** (E Van Eycken). Very sincere thanks and congratulations to all those who collaborated.

**14. Report of the financial committee** (FP)

- a) **extended support for ad random TME assessment by the pathology board**  
no change (cfr 11/2009)
- b) **Statistical consulting (for an equivalent of 0.5 FTE) for analysis with risk adjustment.**  
no change (cfr 11/2009)
- c) **Review of CT/MRI via PROCARE RX.**  
no change (cfr 11/2009)

**15. Varia**

PROCARE meeting on national databases, feedback and quality control (UK, S, N, ...). **Decision: to be done in 2011 (first half?)**

**16. Period of next meeting.** October/November 2010.

**Adjourn 22.00**