PROCARE
PROJECT ON CANCER OF THE RECTUM

AGENDA of the PROCARE **STEERING GROUP**
9 November 2010
Place: RIZIV/INAMI, Tervurenlaan 211, Brussels, 8th floor **room Permeke (entrance via car parking St Michielscollegestraat 69)**.

Minutes of the Steering Group

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

The underlined colleagues have confirmed their presence.
Apologies were received from: Peeters, Mansvelt, Haustermans, Laurent, Haeck, Demetter, Van de Stadt, Danse, Op de Beeck, Pattyn, Van Cutsem, Dercq. Smeets (21/11 because abroad).

Present: Bertrand, Claeys, Duinslaeger, Jouret, Kartheuser, Penninckx, Sempoux, Spaas, Vaneerdeweg, Van Eycken, Thijs A, Vandendael Tamara (datamanager PROCARE op FBCR).

Start 20.00

1. Minutes 20 April and 12 May 2010. Have been approved (cfr www.registreducancer.org under PROCARE, publications, minutes).

2. KCE project on risk and volume adjusted analysis for benchmarking and feedback (PDM or FP):
Clinicians delegated by PROCARE are:
oncology: Van Cutsem, Van Laethem, Laurent, Vandeneynde
radiotherapy: Haustermans, Scalliet
pathology: Demetter, Nagy, Jouret
BPSA: Vindevoghel Koen, Molle Gaetan
Surgery: Ceelen, Van de Stadt, Kartheuser
Radiology: Danse
PROCARE database: Penninckx, Van Eycken

PROCARE clinicians tasks (co-ordination P Demetter):
- QCI : identification of new indicators. Done.
- Targets for QCIs. Done.
- Clinically relevant factors for adjustment. In process.
- Identification of most relevant QCIs and set(s) of QCIs. Done.

PROCARE data deliveries:
- temporary data. Done
- follow-up data: reminders sent on 12 september 2010

- definitive data. Will be done per November 15, 2010

Demand of KCE: Deliverable 7. PROCARE database (2006-2008) coupled with BCR database on rectal cancer (2006-2008) by Belgian Cancer Registry (BCR) Liesbet Van Eycken, Koen Beirens. Evaluation of the exhaustivity of the PROCARE data and an estimation of the (intra)hospital participation in Procare. Information (not the data?) to be transferred to the UGent researchers. Timing: T0 + 7.5 mths (**1.2.2011**). **Decision: Of interest, but not in the scope of the KCE-PROCARE phase III project (aiming to provide a statistical method for adjusted benchmarking on the existing PROCARE database). Nonetheless, within PROCARE this aspect will be studied and reported (as already planned from the start, but not yet done because FBCR data of 2007 and 2008 will be available by the end of 2010). Several caveats have to be taken into account anyway, e.g. teams started participation in PROCARE at any time (will be solved by counting from the incidence data of the first patient submitted to PROCARE), definitions of rectal cancer may well be different in PROCARE (0-15 cm, invasive adenocarcinoma only) and FBCR registrations through MDT meetings and pathology reports (will partially be solved by checking every patient from participating teams not submitted for registration in PROCARE DB), many cStage IV patients with metastatic disease, of whom several can be expected not to undergo radical resection (13% of pts registered for PROCARE feedback 2009 had cStage IV; about 271/305 or 89% of these underwent resection), are not submitted for registration in the PROCARE DB until now. The analysis of demographic data (age, gender), tumour staging, outcome (postoperative mortality if operated; observed and relative survival) will be performed by PROCARE and FBCR. Results will be part of the PROCARE report to the RIZIV/INAMI. The Steering Group realizes that not including adjustment for missing patients may be a shortcoming of adjustment of data in a database with registration on a voluntary basis (such as PROCARE). However, this type of adjustment is not required in a complete database. At the end of the PROCARE project it will have to be decided whether registration of detailed data on patients with any stage of rectal adenocarcinoma should become obligatory or not.**

3. PROCARE database

a. web application (EVE). Launched September 14, 2010.

b. evolution of participation and patient entries

The aim is that in 2011 >75% of the hospitals will participate.

Taking into account recent hospital fusions 83/111 (75 %) hospitals participate.

3403 patient data sets in database (3755 cases submitted but 352 excluded).

c. the list of participating centers per year (y/n) will further be mentioned on the PROCARE website. Should the number of patients (with at least pretreatment data) be added to the table per center and per year of participation? **Decision: not the number but the percentage of patients should be mentioned per year of participation (starting with the incidence date of the first patient entered) and can only be done from the end of 2010 when FBCR will dispose of data on all patients with rectal cancer in 2006, 2007, 2008. If feasible, the data in the table of participating teams with be 'updated' in this way, but the decision has to be approved in the 2011 spring meeting.**

4. PROCARE feedback: (FP)

The second feedback was given to all participating teams in 12/2009.

A specific effort to obtain relevant data on adjuvant treatment, local and/or distant recurrence was done via mail to all participating teams.

The third feedback will be delivered before December 25, 2010. Analyses are made by Koen Beirens at the FBCR after update and 'clean' the database (Tamara + FP + FBCR). **Decision: the global results will be pre-circulated to the Steering Group before feedback will be sent to all participating teams.**

These documents will be available on the website as before. More QCI will be included.

Feedback was not given as planned in June 2010 due to interference by the KCE-PROCARE phase III project and the shift towards web application for data entry.

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

a. TME training : 4 surgeons have been trained, 2 are in training.

b. A reminder about the possibility of TME training was sent together with above mentioned mails.

It is confirmed that TME training will not reach the 'volume' that had been anticipated based on 'intentions' at the workshops in 2005. Reallocation of the related budget has been planned. **To be re-approved**.

6. TME review Pathology Board (AJ)

The pathology board centrally reviewed 163 TME specimens at random (+ 45 specimen planned for review in 11/2010). This process will be continued on a ½ basis of incoming TME cases, but this may be re-adjusted according to submission rate.

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

The pathology board produces an evaluation form per specimen. **Decision: 1) the pathology review information will be sent to the submitting pathologist by the datamanager at the FBCR. 2) as soon as available global results of pathology review of all TME's coming from participating teams will be sent to the team with the bi-annual feedback.**

7. PROCARE RX

After being tested by 6/9 radiologist-reviewers, PROCARE RX was launched on 1st May 2010.

Submissions for review: 11 (per 0ctober 15, 2010). **Discussion** : to be (re)activated? How?

Mail ED: We did a lot of effort for the diffusion of the info, using the channel of the UNR-NUR (connected to the GBS), and the Belgian Radiologist Society. The option could be to send a letter to the clinicians (mainly surgeons) responsible for the muldisciplinary oncologic discussions, where radiologists are presents, in order to tell the leaders to stimulate the radiologists to ask a second opinion. For me, the best way to stimulate radiologists is the power of the clinicians.

Decision: No workshop. Letter to be sent to chairmen/ladies of MDT, LOK/GLEM and the Presidents/Secretaries of the participating scientific and professional societies.

8. Radiotherapy and PCE. (Spaas)

There are 25 radiotherapy centres in Belgium. Radiation oncologists started with peer-review in the 1990's. However, the actual platform appears to be highly appreciated and used. After being tested in 2009, PROCARE - RT was launched in March 2010 (March and April were "test" periods with only 3 or 4 centres). Submissions for review: 189 from 18 centers (per October 15, 2010). Archiving the data is required for further studies and comes with costs that have not been planned.

Decision: the Steering Group will ask the RIZIV/INAMI to allow that these costs would be covered by financial support not being used for other aspects of training. Mail of FP dd 15/11/2010.

9. Guidelines (and Quality of Care Indicators): an update is appropriate.
Proposal for organisation:
Pretreatment staging: Danse & Op de Beeck
Neoadjuvant treatment: Haustermans & Scalliet
Surgery: Kartheuser (Leonard) & Penninckx
Pathology: Sempoux & De Metter
Adjuvant treatment: Demey & Van Cutsem
Palliative treatment: Laurent & Peeters
Follow-up: Cabooter & ?
Decision: approved.

10. EURECCA (European Registration of Cancer Care) (FP). Meeting in Bordeaux (ESSO) on September 16, 2010. Document attached. What type of data can/will be transferred?
Decision. 1) agreement in principle to participate because it would give the opportunity for international European benchmarking in the future. 2) related to 7.d) and 7.e): "A procedure to respect the privacy of the data will be established and applied to all data." and "Each Center is responsible to obtain individual patient authorization to load that patient's data in the EURECCA-CDB", Dr Dercq and Mr Thijs advised as follows: Het opnemen van de patiëntgegevens in de administratie in het kader van de zorgverstrekking (in ruime zin) vereist geen enkele toestemming van de patient. Wanneer de finaliteit van diezelfde gegevens - in het kader van kwaliteitsprojecten – wijzigt is de (schriftelijke) toestemming van de patiënt nodig. P.S. dit geldt niet voor geanonimiseerde patiëntgegevens maar geldt wel voor gecodeerde gegevens. Het vragen om een toestemming van de patiënt tot gebruik van (zijn) patiëntgegevens in het kader van kwaliteitsprojecten is zeer gebruikelijk. Op termijn is het systematisch vragen van een individuele (schriftelijke) toestemming tot het gebruik van patiëntgegevens voorafgaand aan de operatie een goede politiek die niet alleen in het kader van nationale kwaliteitsprojecten dienstig kan zijn, maar eveneens in het kader van internationale uitwisseling van gegevens zoals bij EURECCA. En zeker in the long term….
Belangrijk is ook dat Procare - in geval van deelname aan EURECCA – zich samen met het Kankerregister dient te organiseren voor wat betreft de inzameling van nationale gegevens opdat deze kunnen overgenomen worden in de EURECCA-DB. 3) Haustermans is candidate to be one (of the max. three) PROCARE delegates. 4) FP will further inform the Steering Group and ask formal permission before signing the EURECCA-colorectal agreement form.

11. Presentations and publications
Francois Joris, Beirens Koen / Penninckx F ask permission to write on behalf of the PROCARE steering group an article about the APR rate in PROCARE and its adjustment for confounding factors. The final draft to be approved by the steering group prior to submission for publication (Colorectal Disease?). **Decision: approved**

Beirens Koen/Penninckx F ask permission to write on behalf of the PROCARE steering group an article about the leak rate after sphincter preserving rectum resection in PROCARE and its

adjustment for confounding factors. The final draft to be approved by the steering group prior to submission for publication (Colorectal Disease?). **Decision: approved**

PROCARE will be present at the Belgian week of Gastro-Enterology 2011 (17-19 febr 2011 in Liège). **Decision: it may be possible (and more effective) if a short communication about all aspects of PROCARE training/review/feedback opportunities/possibilities could be given. CS and EVE/Tamara will follow up.**

Pro memoria:

a. plans of pathologists
    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 Procare "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. **Remark: the fact that data from the PROCARE DB were used should be appropriately acknowledged.**
b. FP (who is candidate to co-write ?): achievements and difficulties of PROCARE after 3 years (Acta Chir Belg) ?

12. Newsletter (E Van Eycken): planned after feedback 2010.

13. Report of the financial committee of November 9, 2010 (FP)

14. Varia

PROCARE meeting on national databases, feedback and quality control. Proposals to be made by all members of the Steering Group before January 31, 2011. To be organised in what format (workshop? Open symposium? when? Where? How to cover costs for invited speakers, participants, location?
Decision: Form: workshop of a whole day (with lunch/diner). Place: RIZIV/INAMI. Participants: limited number incl. Steering Group + expert-clinicians from any interested team/network (to be suggested by SG members before 31/01/2011). Costs for participants and invited foreign clinical experts: will be covered by RIZIV/INAMI support already available in the PROCARE budget. Timing: end of 2011? (to be decided at the SG meeting in the Spring 2011). Program: to be decided at the SG meeting in the Spring 2011.

15. Period of next meeting. April 2011.

Adjourn 22.00