

## PROCARE PROJECT

Minutes of the MEETING of the PROCARE working group  
Monday 30<sup>th</sup> January 2006 at 20.00 until 22.30

Place: Leuven, Faculty Club, Huis van Chièvres, Sint Gommariuszaal  
Sandwiches, dessert, coffee, and drinks were served

Invited:

e-mail list

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Present: burnon, claeys, danse, duinslaeger, ectors, jouret, kartheuser, penninckx, scalliet, spaas, van de stadt, van eerdeweg, van Eycken, hermans, sempoux

1. Welcome with summary of the state of the project and aims of the meeting
  - Registration at NCR (started for candidate-instructors, all surgeons)
  - Retrospective study manuscript submitted and accepted (Acta Chir Belg)
  - Radiology workshop planned (Jan 2006)
  - Financial support from Foundation against Cancer, RIZIV/INAMI
  - General principles of implementation
    - No team can/should be excluded
    - Decentralized implementation with support (instruction, review)

Central registration (with data quality control)  
Feedback to teams

## 2. Multidisciplinary Guidelines

- a) Update required : proposal of updated version was pre-circulated and accepted, but some text to be provided for radiology (danse), pathology with adapted report sheet (ectors), oncology (?). Plan: updated in half February 2006.
- b) permission to the College of Oncology to use the PROCARE multidisciplinary guidelines (request from Peeters M): yes
- c) permission to the Society of Radiology to use the PROCARE guidelines (request from Danse E): yes

## 3. Administration of financial support

- a) Foundation against Cancer: proposal at the NCR : Van Eycken E
- b) KCE: depending on further procedure; Penninckx received a call from ramaekers dirk on 2 february 2006 to say that we should apply via the KCE website. Penninckx will send a separate mail to the working group on 3 febr 2006. To be decided urgently thereafter (cf. submission deadline).
- c) RIZIV/INAMI: PROCARE working group p/a Penninckx F at UZ Gasthuisberg (no overhead). According to information from De Coninck, a 'Feitelijke Vereniging – Association de Fait' of all societies involved will have to be set up. Penninckx (in collab. With De Coninck) will propose a letter to be sent to the presidents and secr.-gen. Of the societies. The letter will be pre-circulated to the members of the working group for urgent feedback. A financial subcommittee (cf. infra) will take practical decisions.
- d) FWO/FRS: the promoter of each project

Internal rules concerning financial administration:

- a) the responsible administrator of all funds (except FWO/FRS funds) circulates an overview (in, out, balance, commitments) every trimester to all members of the PROCARE working group.
- b) the administrator of a fund is not supposed to take specific initiatives 'ex officio'. Initiatives should come from any society/association represented in the PROCARE working group. Deviation from the originally planned allocation of costs is not allowed.
- c) In case re-allocation of planned costs would seem to be appropriate, the administrator must ask written permission, in advance (i.e. before costs or commitments are made), to a financial subcommittee consisting of: the chairmen of the project, the director of the NCR, 1 delegate per discipline (radiology, radiotherapy, surgery, pathology, oncology, internal medicine), 1 delegate of the professional organisation of specialists. The global 'welfare' of the project will have to be respected. A decision will be taken by simple majority.

Delegates in the financial subcommittee:

Chairman of the project: Penninckx F  
Director of the NCR: Van Eycken E  
Delegate radiology: Danse E  
Delegate radiotherapy: Spaas P

Delegate surgery: De Coninck D

Delegate pathology: Jouret A

Delegate oncology: Van Cutsem E

Delegate gastroenterology: Melange M was proposed and accepted, but the SRBGE decided to delegate Polus M (cf. e-mail of Melange, Van Laethem and Kartheuser dd 3 feb. 2006 (circulated to the working group by Penninckx on 3 feb. 2006).

Delegate professional organisation of specialists: Mansvelt B

#### 4. Working at the NCR

a) Mrs. Hermans Frie, data manager at NCR (funded by Foundation against Cancer for 2 yrs)

b) 1-2 more datamanager for data control and help 'on the field' (funded by RIZIV/INAMI)

c) installation of a PROCARE website at NCR (for registration and newsletters). Contacts with Fit-IT. An offer from Fit IT for webregistration was made; the budget estimate ranges from 50.635 – 61.290 (+ VAT) € .

d) no copy of any part or of the whole database at the NCR will be distributed to any person, society or instance. A specific agreement is to be made between NCR and PROCARE working group and FV-AF PROCARE.

e) Newsletter from the NCR

- contents:

1) news from any society/association (planned activities);

2) news from the NCR: N of participating teams (named; with geographical map), N of registered patients, N registered patients/centre, further data on staging, treatment, follow-up as evolving.

- responsible editors: EVE + other(s) by invitation on behalf of the PROCARE working group

- distribution:

a) from NCR

b) to each society/association (to be put on their website) and to the contact person or participants in each participating center (e-mail).

c) frequency: trimestrial (4 x / year)

f) PROCARE delegates. It is important that delegates of the PROCARE working group (potentially and preferentially coming from outside the group) should be working part-time (e.g. ½ day per 1 or 2 weeks) at the NCR. They should perform:

- check the quality of the anonymous data (with the datamanager)

- perform research work concerning their discipline/project

- prepare newsletter (to be sent to all participating teams)

- survey of the quantitative aspects of registration on anonymous data (N of participating hospitals, N of patients/hospital, consecutivity of patients)

- .../...

Proposal of delegates (have confirmed interest):

Penninckx F (1 d / 2 weeks)  
 Leonard Daniel, trainee-surgeon at UCL  
 A pathologist: ...  
 A radiologist: Danse Etienne  
 A radiotherapist: ...  
 An oncologist: ...  
 Socio-economic aspects: candidate of Peeters M  
 .../...

Delegates working at the NCR on the PROCARE database could perhaps be remunerated through a European grant to the NCR (LVE) of about 15000 €/yr

#### 5. 'Relationship' with KCE (if funding from KCE) and/or IMA

The KCE wants to avoid 'double efforts' as much as possible.

The following aspects could be studied in collab. with KCE (and IMA?).

- quantitative aspects of participation: monitoring of recruitment (hospitals, patients)
- audit of the quality of the data
- audit of the implementation of the guidelines
- cost/benefit aspects of the project (also in collab. with IMA? For financial data)
- .../... ?

Proposed 'strategy': wait and see; speak with Prof Ramaekers Dirk.

NB. Cf. specific separate mail.

#### 6. Radiological aspects of GL implementation (ED)

- documentation: criteria for cTN(M) staging to be inserted in the GL. CDrom to be produced by Danse E, Smeets P, Van Beckevoort D, Bielen D, incl. images from Beets-Tan R and Brown G
- workshop for radiologists will be organised in May 2006 (based on e-mail list of radiologists cf. Danse E)
- Central review of cTNM staging of individual patients by 5 radiologists delegated by the RBSR (via Telemis).

Dr Danse has sent the following mail-text to his colleagues in the 'review team':

Keep in mind that all the data (including images and pathological samples) are collected in the National Cancer Registry (NCR), in Brussels, on an anonymous way.

- reviewing process : + ***budget from Procure***
  - o who : Dirk, Didier, Peter, Bart, Etienne
  - o where : **to be decided** ( National Cancer Registry, or ... with teleconsultance « telemis software »)
  - o when: pre-operatively or "a posteriori"
  - o **which modality** ?
    - with CD and on a dedicated PC ?
    - with Teleconsultance ? Telemis will be used by radiotherapy Procure group to optimize and manage the radiation doses between each participating staff because it allows a rapid imaging transfert.
- training: + ***budget from Procure***

- information :
  - Procure meeting of the 26-01-06
  - Article in the next issue of the JBR
  - **CD and edited guidelines**
    - Guidelines (to be updated): initial version on the web site
    - CD : to be done (with presentation of Dirk)
  - Newsletter (coming from the NCR, with information from each association involved in the Procure)
- Formation :
  - **Workshops : in may 2006** (if possible on Saturday, 13-05-06) :
- Research:
  - Publications can be done with the collected material ( request of young researchers in the different academic hospitals).
    - **We have to contact all the interested academic hospitals**

## 7. Radio(chemo)therapeutic aspects of GL implementation (KH)

- Indications and methods : cf. GL and atlas
- Central review of RT technique in individual patients: Telemis platform, initially check data in 1/10 patients, later 1/5 and ultimately in all patients (incl. dosimetry checks). Retrospective in the beginning, later prospective.
- Organised by BSRT0 for all 26 centres in Belgium.

## 8. Surgical aspects of GL implementation (DDC, CB)

- Documentation:
  - main protocol (illustrations): by the BSCS? Who?
  - DVD: AK makes a DVD of the workshop-procedures by Heald.
  - Alex wrote on 4 February 2006:
    - comme convenu il s'agirait plutôt d'un DVD qui outre les interventions de Heald et Quircke reprendrait :
      - les différentes présentations Power Point du Procure (version chir, anapath, radio, .... )
      - les guidelines
      - la check-list de la data-base.
    - Une offre de prix sera d'abord demandée au CAV de St-Luc qui a fait une excellente prise de vue en per-op.
    - Ce DVD devara être prêt pour être distribué à la BWS à Ostende le vendredi 5 mai
- TME training (for those who want it)
  - a) candidate-trainers:
    - registration started in October-November 2005
    - selection by BSCS (on the pre-set criteria)
  - b) candidate-'trainees': list at the BSCS and BPSA (based on workshops)
  - c) organization of training by BSCS and BPSA
    - list of trainers on website of BSCS and BPSA with availability/region, .../...
    - max. N of demos/trainer?

## 9. Pathological aspects of GL implementation (NE, AJ, CS). Sempoux Christine (UCL) will also be delegate on behalf of the GI Pathology Club from now on.

- documentation: Criteria for (y)pTN(M) staging cf. GL and CDrom

- Central review of pTNM and pCRM staging of individual patients by delegates from the board of the DPClub (in UCL/KUL) on Saturday mornings. All specimens of candidate-instructors will be assessed. From the prospectively registered patients an at random sample of 1/10 à 1/15 will be assessed for quality control.
- Who organises DPCI in collab. with NCR

10. Oncological aspects of GL implementation (EVC)

- Entry data form to be adapted (**cf. MP and EVC to be sent by separate mail**)
- GL to be updated
- Central review of data of individual patients (how? Who? Remuneration?).  
No decision.
- no specific workshops needed

11. Public launch of the PROCARE project to be postponed until 1-2 years after the start of the project, i.e. mid-end 2007

12. Booth at the BGEW February 2006 (1 day only) and BSW May 2006 (on Friday only). Costs: we hope none. Who is there: datamanager. What is presented: poster, guidelines with links for updating, data entry form on CDrom if form for participation (with personal data incl. e-mai) is filled in.

13. Publication policy : postponed (document to be prepared)

15. Need for a executive committee (within the working group) to organise practical aspects of the project. No standing committee, but 'ad hoc committee(s)' depending on the need and the candidates (from the working group).

16. Digitalized photo of the working group was made for the Foundation against Cancer

17. Adjourn at 22.30

18. Dr Polus M (CHU, ULg) will replace Van Laethem JL and Mélange M (SRBGE).  
E-mail with approvals of Mélange and Van Laethem received on 3 Febr 2006.