PROCARE

PROJECT ON CANCER OF THE RECTUM

July 2008 Volume 1, Issue 1

Special points of interest

Dear colleagues collaborating in the PROCARE project,

Congratulations to all of you because the project is advancing well with more than 1500 patients in the registry. You have all experienced the burden of work for registration. Your efforts will soon be rewarded with the first feedback of your patients and of all those included in the database. In view of the early stage of the project, no comments will be attached to the feedback. However, in a later stage, analysis with risk adjustment will be performed where appropriate. Indeed, risk adjustment is mandatory for correct interpretation of the results, but requires complete data and, very importantly, adequate application of definitions.

This Newsletter has been approved by the members of the Steering Group and contains a lot of information. The following items are worthwhile to be highlighted:

PROCARE website at www.belgiancancerregistry.be contains all information you need.

From August 1, 2008 an updated data entry set has to be used for all new patients.

Oncologists are asked to include Stage IV patients.

A platform for review with feedback on pre-treatment radiological staging will soon be available. Inform your radiologist(s)!

The second part of the PROCARE/KCE project on quality of care indicators is just finished and is available on www.kce.fgov.be/index_nl.aspx?SGREF=10500&CREF=11263.
Read the document. The Quality Indicators will be used for feedback.

TME training is ready to start.

The Steering Group thanks you in advance for your continued support and registration of all consecutive patients. We hope that even more colleagues will join this multidisciplinary, professional and decentralised project in the near future.

The PROCARE Steering Group

News from the Surgeons ...

Dear Colleague-surgeons,

We are very pleased to announce you that we are ready to start the TME training.

Twelve surgeons have been selected by the BSCRS board, with the help of the pathologist board. In the near future, we expect to have a few more trainers (in particular French speaking) as the selection job is still running and some surgeons are very close to fulfil the criteria.

The list of trainers will not be published in order to respect privacy and to gain anonymity. If training is needed, the demanding surgeon must contact Dr. Liesbet Van Eycken. She or one of her collaborators will provide the name of two trainers as well as the modalities to reach them.

The training modalities have been decided by the BSCRS and the BPSA. They are available on the BPSA and BSCRS websites via www.belsurg.org .

The second and as important aspect of Procare is the registry. Today, more than 1550 cases from 60 different hospitals have been registered.

As one can understand, it is crucial to continue to register all patients with rectal cancer. In order to keep an intact motivation, the BCR will send to each surgeon, before the end of August 2008, a feedback comparing the registered cases to the entire database (benchmarking). This is a very important point to keep an intact motivation in registering the cases.

Everyone knows probably by now that financing for the Procare project is supported by the RIZIV/INAMI. This financing covers the costs for registering and analysing the data, for feedback and training. This means that with your help, the goals of the project are within our reach: registration of the therapeutic outcomes of all rectal cancer patients in Belgium, feedback to the participating teams and support in insuring the expected quality of care anywhere in the country.

It took much longer than we expected. We definitely underestimated the cumbersome steps to be taken and the administrative obstacles to be overcome. We would not have succeeded without the whole hearted and effective support of the administration of the RIZIV/INAMI, who led us efficiently through this mill. We truly are grateful for their help and support.

We are aware that support can lead to suspicion and that some of you might feel tricked into giving a helping hand to some sort of “Big Brother”. This is not so. In fact, assessing the quality of healthcare has become increasingly important to providers, regulators and purchasers of care in response to growing demand for services, rising costs, constrained resources and evidence of variation in clinical practice. Whether we like it or not, our performances will be put to scrutiny. There is no choice on that. The choice we do have is whether we will leave this to be done by governmental instances and statisticians, economists or epidemiologists who are not familiar with the clinical challenges we face daily, or whether, as a profession, we will visibly and effectively assume that responsibility.

There is substantial evidence that profession-led and profession-driven quality improvement programs are far more effective than external interference, whether in the form of incentives (financial or others) or in the form of sanctions. The scientific organisations of physicians caring for rectal cancer patients in Belgium are in fact happy that the Health Authorities of the country share that view and give us the opportunity to put it into a test. This is a unique opportunity we all have to seize, especially those working in smaller and non academic centres. It is up to us to demonstrate that given the right educational support, we are up to the task. It is also very important to consider that all data are anonymized by the BCR before being communicated to anyone, including of course KCE as well as INAMI/RIZIV.

We realise that complying with the requirements of the registration is cumbersome. We would like to remind you however that this is not to be the work of one person, but should be a joint effort by all members of the medical team involved in the diagnosis and treatment of rectal cancer.

As far as the registry is concerned, we are over 1400 registered patients and this is the figure we set forward for benchmarking and feedback to all participating centres. This is quite a success compared to the recruitment in other countries in the two first years of analogous projects.

Till now, only the TME cases of the surgeons who are willing to become trainers for their colleagues were reviewed by the pathology and surgery review boards. Indeed, since about half of the surgeons willing to participate in Procare (and this is 80% of all general / abdominal surgeons in the country) expressed the wish to have the possibility of tutorship and support by a colleague with a certified capability. Selecting those tutors was an urgent priority. Until now, 12 surgeons have fulfilled the criteria. On that topic, there is a need to clarify some misunderstandings. Obviously, more than 10 to 20 surgeons in Belgium are capable of performing a correct TME. Thus, becoming a trainer should not be considered as some kind of "exclusive" quality label. In fact, being able to perform a TME adequately is only one of the expectations from a trainer. He or she also has to be available for support of a colleague in his operating room and willing to do so. Quite a few very capable colorectal surgeons (academic or not) do not have the latitude to do this and did not wish to become a "trainer". Therefore we would like to stress once again that it would be absolutely un-deontological to express any judgement on anybody's competence based on his being "trainer" or not, or to boast about his own trainer-ship status. This would be quite an unprofessional attitude. Trainers with unprofessional attitude will be removed from the list of trainers (BPSA and BSCRS to decide).

Meanwhile 352 cases of candidates trainers have been analysed and feedback given to them. This too raised some questions, mainly regarding the pathological evaluation.

A large proportion of cases are deemed "not evaluable". This is mainly due to the lack of valid photographic or other evidence of the integrity of the TME. There seem to have been some misunderstandings with the pathologists on that point but that should be cleared out by now. Another major misunderstanding concerns the extent of resection. Please note that only TME's are evaluated: a PME, although perfectly executed cannot be taken in account since evaluation of candidate trainers is on TME only.

Finally, of course surgeons must realize that the pathologist can only express a judgment on the quality of the specimen. It is appreciated that not all rectal surgery is easy. Many confounders are present in a patient and determine the pathological quality of the specimen. Obviously, at the time of pathological evaluation these are not taken into account. So here again, pathologists do not express an opinion on the quality of the surgery performed, but solely on the quality of the specimen they see.

Procare seems to be the best multicentric and multidisciplinary project ever held in Belgium. We feel proud to promote it, and we hope that everyone will keep his enthusiasm intact as long as needed to reach the goals of the project.

Brussels, 2nd of July 2008

Dr. Daniel Deconinck Dr. Constant Jehaes Dr. Luc Haeck

Procare TME training modalities

As proposed by the PROCARE Steering Group, TME training organisation and its modalities have been decided by the BPSA and the BSCRS. They are available on the BPSA (Belgian Professional Surgical Association), and BSCRS websites: www.belsurg.org. In brief:

The list of trainers will not be published.

When training is wanted, one must contact Dr. Liesbet Van Eycken, via mail procare2@kankerregister.org.

Dr. Liesbet Van Eycken or one of her collaborators will indicate two (if possible) names of potential trainers, respecting the following criteria: participation in the PROCARE project, language, laparoscopic or open surgery, availability of the TME trainers. The demanding surgeon will make the last choice and contact himself the chosen trainer.

In principle, training consists in assistance by a TME trainer at 5 consecutive TME procedures. Each trainer surgeon is allowed to train two (or more if needed and if possible) surgeons.

The trainer will go to the trained surgeon hospital, and will help the local surgeon to perform the TME (Note that the training is only for TME and not for PME!!).

The trainer will receive a 525€ fee per case (but only after training has been completed).

The specimen must be evaluated according to the Quirke methods. A description can be found at the PROCARE website www.belgiancancerregistry.be . Of course, the patient also must be introduced in the PROCARE registry through the BCR.

Inform Dr. Liesbet Van Eycken who will further coordinate the TME training, per trained procedure, mentioning the name of the trainer, the name of the trained surgeon, date and type of procedure (LAR with/without pouch, APR), any other remark…

Send this mail in cc to Prof Penninckx, chairman of the PROCARE Steering Group at freddy.penninckx@uz.kuleuven.ac.be, who is responsible for reimbursement.

Dr. Luc Haeck Dr. Constant Jehaes Dr. Baudouin.Mansvelt

Contact address TME training
PROCARE
Dr. Liesbet Van Eycken
Stichting Kankerregister-Fondation Registre du Cancer
Elizabeth.VanEycken@kankerregister.org
Koningstraat 215 - 1210 Brussel
Tel 02 250 10 13 - Fax 02 250 10 11

News from the Oncologist ...

Dear Members, colleagues and friends,

Treatment of rectal cancer in a multidisciplinary approach is mandatory for a better patient outcome

Besides the optimal surgery and radiotherapy, integration of medical therapies is a major issue to optimize the treatment of rectal cancer in Belgium. PROCARE has already a positive impact on the quality of care of rectal cancer patients. In the line of this quality improvement, it is also important to collect information on the medical treatment, more precisely on the chemotherapy.

Oncologists are involved in the therapeutic decisions and guide the patients through preoperative setting during the radiochemotherapy, in the adjuvant treatment, and also in the metastastic and palliative setting.

Systemic treatment has three major aims:

1. To enable curative surgery and prevent local recurrences.
2. To prevent metastatic disease after complete surgical resection

To prolong survival, control symptoms and improve Quality of Life in patients with advanced or metastatic disease.

Since a few years, an important progress in systemic treatment has been made. In patients with metastatic disease, an improvement of survival rate from 6 months to more than 24 months has been obtained. This significant increase in life expectancy has become possible though the introduction of irinotecan and oxaliplatin, agents now considered as standard chemotherapy treatment. Oral fluoropyrimidines are on their way and replace more and more parenteral fluorouracil, not only in single drugs regimens, but also in the new and effective combination protocols. The development of targeted therapies against VEGF and EGFR will in the future contribute to the multiplicity of the possibilities. The availability of all these drugs has also a major impact on the survival.

The completion of the data entry form of chemotherapeutic aspects in the PROCARE will allow an evaluation of the systemic therapies given in rectal cancer in Belgium. It will provide very important data on toxicity and on dose-intensity. We encourage the oncologists in Belgium to participate to the PROCARE project, which is a project of all the professionals involved in the treatment of rectal cancer.

Dr. Stéphanie Laurent and Prof. Dr. Marc Peeters

News from the Radiologist ...

A platform for review of preoperative radiological staging

Dear Members, colleagues and friends,

The aim of this part of the PROCARE project is to organize a second look of the radiological staging in patients having a rectal cancer. This second lecture should be done before treatment. A 'platform' will be constructed soon and works as follows.

The pre-treatment staging of rectal cancer, including T, N, M and CRM data is initially done by the radiologist involved in the management of the patient (the sender). A second opinion is given by a reviewer radiologist, dedicated and subspecialized in abdominal imaging. This is done in a positive way (quality control) and in an anonymous setting concerning the data of the patients, and the radiologists accepting to participate in the project.

An online and web based system will be set up by EBIT. Such a system requires strict safety measures. The collaboration with the Belgian Cancer Registry (BCR) facilitates the use of already existing online authentication procedures (with eID or token) and hosting possibilities. The authentication procedure runs through the services of e-health, already used by at least 50 Belgian hospitals. The application itself and the data base will be managed by the BCR. The local administrators of the hospitals responsible for the e-health services will be able to provide access to the radiologists. Radiologists accepting to collaborate in this project will have to ask their management (administrator) to install the user rights for this web-based application.

Radiologists participating in the project send the imaging data, including CT and/or MRI (dicom format) to the application hosted by the BCR, AFTER anonymisation of the images by using local PACS solutions commonly available. They have to answer to a question confirming that they send anonymous data. The "uploaded" or "sent" examination is initially labeled with a specific identification number. Then, there is first an upload of the data in the data base, together with the transmission of the TNM staging of the rectal cancer using this platform. The confirmation of a successful upload is done by a return e-mail to the "sender" radiologist.

The reviewers are doing a second look of the uploaded and anonymised examination, transmitting their own findings onTNM and CRM. In case of discrepancy between the first opinion and the second, a comment is inserted on the web page and a second review is generated for a conclusive third opinion. The second reviewer sends feedback to the sender and the first reviewer. This process is based on experiences in screening mammography. These informations (confirmation of the staging, or another proposition of stadification with comments) are sent to the "sender" radiologist by e-mail. The way the "sender" will use these conclusions is free, but can be presented by this radiologist at his multidisciplinary discussion

It is suggested to the participating radiologist to inform the local multidisciplinary team (MDT) that he has send the imaging data of a patient to the BCR. He can transmit to the MDT the identification number of the patient in order to create a link between the PROCARE data entry set and the anonymous images sent to the BCR platform.

Thus, first of all, radiologists participating in the project will have to ask their administrator-management to organize/install/activate access to the e-Health platform, in order to have a secure web access. E-health will be the platform used by participating (sender) and reviewer-radiologists.

Dr. Etienne Danse

Participating Hospitals

Overview of hospitals who participated in the Procare Project (updated 01/07/2008)

Antwerpen	Liège
AZ H. Familie Reet	CH du Bois de l'Abbaye et de Hesbaye Seraing
AZ Klina Brasschaat	CHC Saint-Joseph Liège
AZ Monica Deurne	**Limburg**
AZ Sint-Augustinus Wilrijk	CAZ Midden-Limburg Ziekenhuis Sint-Franciskus
AZ Sint-Elisabeth Herentals	Regionaal Ziekenhuis Sint-Trudo Sint-Truiden
AZ Sint-Jozef Malle	Virga Jesse-Hasselt
AZ Sint-Maarten Duffel-Mechelen	Ziekenhuis Oost-Limburg
AZ St-Dimpna Geel	**Luxembourg**
H. Hartziekenhuis Lier	I H Famenne Ardenne Condroz Aye- Hôpital Princesse Paola
H. Hartziekenhuis Mol	**Namur**
Imeldaziekenhuis Bonheiden	Cliniques Universitaires de Mont-Godinne
Sint-Vincentiusziekenhuis Antwerpen-Mortsel	Clinique Sainte-Elisabeth Namur
St. Elisabeth Turnhout	**Oost-Vlaanderen**
St. Jozef Turnhout	AZ Jan Palfijn Gent
UZ Antwerpen	AZ Maria Middelares Gent
ZNA Jan Palfijn Merksem	AZ Oudenaarde
ZNA Middelheim Antwerpen	AZ Sint-Elisabeth Zottegem
ZNA Stuivenberg - Sint-Erasmus Antwerpen	O.L.Vrouwziekenhuis Aalst-Asse-Ninove
Brabant-Wallon	UZ- Gent
Clinique Saint-Pierre Ottignies	**Vlaams-Brabant**
Brussel - Bruxelles	AZ Jan Portaels Vilvoorde
UZ Brussel	Regionaal Ziekenhuis Heilig Hart Leuven
CHIREC Bruxelles - Autres sites	Regionaal Ziekenhuis Heilig Hart Tienen
CHU Brugmann Bruxelles	UZ Leuven
Clinique Sainte-Anne - Saint-Remi Bruxelles	**West-Vlaanderen**
Cliniques de l'Europe Bruxelles	AZ Groeninge Kortrijk
Hôpital Erasme Bruxelles	AZ Sint-Jan Brugge
Institut Bordet Bruxelles	Gezondheidszorg Oostkust
Kliniek Sint-Jan Brussel	H.-Hartziekenhuis Roeselare-Menen
Le Centre du Cancer des Cliniques Universitaires Saint-Luc	Henri Serruys Ziekenhuis AV Oostende
Hainaut	OLV.Lourdes Waregem
Centre Hospitalier de Jolimont-Lobbes La Louvière	Regionaal Ziekenhuis Jan Yperman Ieper
CHR de la Haute Senne Mons (=Soignies)	Sint-Andriesziekenhuis Tielt
Clinique Notre Dame Tournai	Sint-Augustinuskliniek Veurne
Clinique Notre-Dame de Grâce Gosselies	Sint-Jozefskliniek Izegem
Réseau Hospitalier de Médecine Sociale Baudour	

News from the Cancer Registry

The registration goes on.....for all teams!

We encourage those teams who already participate to continue the efforts! We warmly and urgently invite all the teams to join the PROCARE project and to register all patients with rectal cancer. Data can be sent to 'Dr. Liesbet Van Eycken', address see below. Within a few days, the actual status of the registration and the statistics will be updated on the website www.belgiancancerregistry.be.

The Registry wishes to thank Mara Huysegoms. Her hard work and commitment made her an invaluable member of the PROCARE team. We wish her the very best for the future.

Recently Isabel de Brito Manique (datamanagement) and Claire Mertens (data analyst) joined the PROCARE team at the Cancer Registry.

Isabel: procare2@kankerregister.org. Tel. 02/250.10.17.

Claire: Claire.Mertens@kankerregister.org. Tel. 02/250.10.12

Online application for the registration: good news!

Thanks to the financial contribution of the RIZIV/INAMI, an online application for the PROCARE data entry will be developed. We hope to make it available for all interested physicians, data managers,... in the automn 2008. We'll keep you informed!

New data set!

From August 1, 2008 , the data entry set will be replaced by a new one. It will be available on www.belgiancancerregistry.be; please do not use the old data entry set from then. A reminder will be sent to all actual participants before the end of July.

Candidate Trainers

Inclusion of candidate trainers is stopped since the 31st of December 2007.

Evaluation of candidate trainers is still going on. A kind reminder for the surgeons and pathologists: Please do check together that all necessary documents and materials are available in order to avoid 'non evaluable cases'.

The Cancer Registry selects in a chronological way the cases to be reviewed by the pathology and the surgery board. The data manager asks the pathologist to send the material to the registry (see also website). (Pathology protocol and pathology check list, pictures anterior and posterior of the UNFIXED TME specimen BEFORE INKING, pictures of all parallel cuts (3-4 mm) of fixed, inked and unopened specimen, all histological slides.)

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P/A
Stichting Kankerregister -
Koningsstraat 215
1210 Brussel

P/A
Fondation Registre du Cancer
Rue Royale 215
1210 Bruxelles