Belgian Cancer Registry

PROCARE

PROJECT ON CANCER OF THE RECTUM

Newsletter 2010

Content:

PROCARE is growing!

We are pleased to send you this PROCARE newsletter. First of all, we would like to thank all the PROCARE-collaborators for their active participation within PROCARE: at the end of 2009, we reached the number of 3000 registrations. Figure 1 gives an overview of the registrations from October 2005, at the very beginning of the PROCARE project, until December 2009.

all the participating centers to continue working with us in this interesting program. You can find the up-to-date list of participating hospitals further in the newsletter (Table 4).

Thanks to the efforts of all participating hospitals, we were able to continue keeping the project on track. Presently, the TME-evaluation of candidate-trainers is finished,

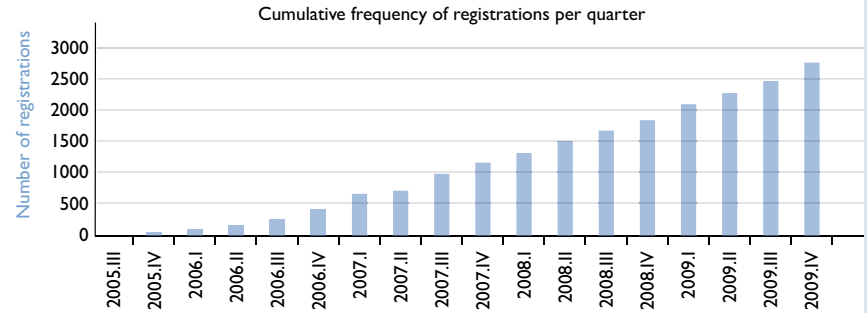

Figure 1. Cumulative frequency of registrations per quarter, October 2005 - December 2009

Although the PROCARE project contains a large amount of the rectal cancer patients in Belgium, there are still some "gaps". Therefore, to increase the number of PROCARE-collaborators, two motivation letters were sent to the surgery departments of all hospitals in Belgium. The first letter was sent to the hospitals which did not yet participate in PROCARE, inviting them to join us. The purpose of the second letter was to motivate

feedback has been given to the participating centers and the paper registration form has been updated. The new version will be used for cases submitted for PROCARE after 1st January 2010 and is available on the website of The Belgian Cancer Registry. Meanwhile, we also started with the at random TME-evaluation of the non-candidate trainers. Table 1 gives an overview of the evolutions within PROCARE.

Evolutions within PROCARE		
Past	Present	Future
- TME-evaluation of candidate-trainers - Feedback to participating centers	- TME-evaluation of non candidate-trainers - TME-teachings - New registration form	- PROCARE Web application - PROCARE RX application - Individual feedback to the pathologists - Radiotherapy Program

Table 1. Past, present and future of the PROCARE project

The TME-evaluation program will continue

The TME-evaluation program of candidate-trainers was finished in October 2009. This evaluation program resulted in 25 recognized PROCARE TME-trainers, 18 Dutch-speaking and 7 French-speaking surgeons. Today, surgeons can be trained with the assistance of these trainers for maximum 5 TME-surgeries. A remuneration of 525 € per case is provided for the PROCARE TME-trainer who will train his colleague. An important condition is - obviously - that these cases are submitted for registration in PROCARE. More information about the TME-trainings can be found on the website of the Belgian Cancer Registry.

As planned, we recently started with the TME-evaluation of the non-candidate trainers. This part of the TME-evaluation program was somewhat delayed because of the large number of cases that was evaluated in the context of the TME-traineeship. Nevertheless, we have started with the at random TME-evaluation of the non-candidate trainers in November 2009. For these TME-evaluations, we made an at random selection of all patients from all participating hospitals. The selection criteria are: (1) TME-cases (not PME!) from every participating hospital, minimum 1 case for each hospital, (2) cases from non-candidate trainers, and (3) date of surgery after July 2007 (this date will be changed, including also older cases).

The at random TME-evaluation will be identical to the TME-evaluation of the candidate-trainers. This means that the Board of Pathologists performs the first review, while the Board of Surgeons takes the final decision. Note that in this process the material is completely anonymised by the Belgian Cancer Registry. No new TME-trainers will be nominated, but each surgeon still will get personal feedback on his or her evaluated cases.

The at random TME-evaluation will continue at least until 2012. When patients are selected, the PROCARE data manager asks the pathologists for the requested material (Table 2), while the surgeons are informed by e-mail. Like mentioned in table 2, digital photos of the fresh specimen are necessary for the TME-evaluation. If it is not possible to bring the specimen in fresh condition to the pathologist lab, please take photos immediately after surgery.

Material necessary for the TME-evaluations

1. Pathology protocol (report) and 'pathology report checklist after surgical resection' (part of the PROCARE registration form)
2. Digital photos of the fresh TME-specimen before inking (ventral, dorsal)
3. Digital photos of the macro-sections (after inking and fixation) and/or macro-slides (if available)
4. Micro-slides

Table 2. Material necessary for the TME-evaluations

Registrations within PROCARE

All patients treated in Belgium (inclusive palliative treatment) for invasive rectal carcinomas (all stages) can be registered within PROCARE. Remark that follow-up of the patient stops in case of local recurrence or metachronous distant metastasis.

At the end of 2009, we reached the number of 3000 registrations. Figure 2 and figure 3 show the registration status in Belgium at the beginning of 2010.

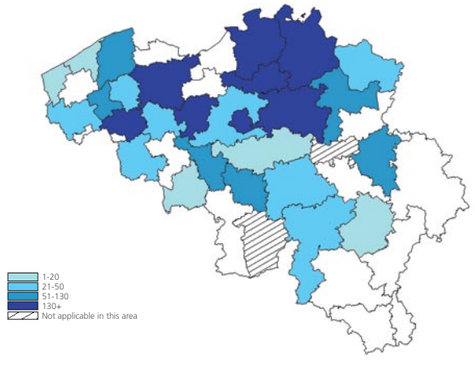

Figure 2. Overview of the number of PROCARE registrations in Belgium by residence hospital and by district, status at the beginning of 2010

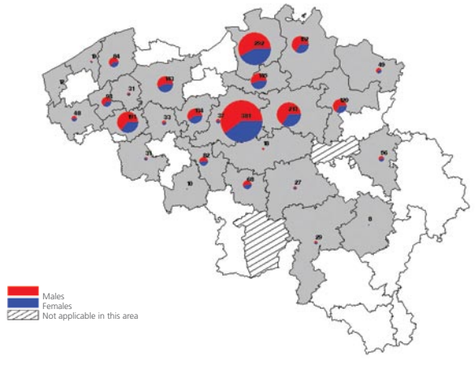

Figure 3. Overview of the number of PROCARE registrations in Belgium by sex, by residence hospital and by district, status at the beginning of 2010

At the end of October 2009, 70 from the 111 Belgian hospitals were participating in PROCARE. At that time, a letter was sent to 180 medical directors and surgeons (53 Dutch-speaking, 127 French-speaking) of 42 non-participating hospitals, inviting them to join us. We received spontaneous reactions from 14 different hospitals, coming from the head of the surgery department, surgeons, gastro-enterologists, oncologists or data-managers. The other 28 hospitals were contacted by the PROCARE data-manager with the help of Dr. C. Bertrand. A lot of hospitals showed their interest to register for PROCARE, in a retrospective and prospective way. Presently, 7 new hospitals (3 in Flanders, 4 in Wallonia) are involved in the PROCARE project, resulting in 77 participating hospitals. The most frequent reactions of the hospitals on call for PROCARE participation are listed in Table 3.

A second letter was sent to centres that stopped or decreased their registration activity since January 2009. This letter was sent to 66 surgeons (38 in Flanders, 4 in Brussels and 24 in Wallonia) to stimulate them to continue with the registrations for PROCARE.

Most frequent reactions of hospitals on call for PROCARE participation

1. The participation will be discussed on moc meetings in the hospital, with gastro-enterologists and pathologists.
2. The guidelines were already followed, but there is no time to do the registrations.
3. The registrations are ready to be sent to the Belgian Cancer Registry.

Table 3. Most frequent reactions on call for participation

We hope these two letters will help to increase the number of registrations during the following months. We estimate that a large part of all the rectal cancers is still missing in the database of PROCARE.

Antwerpen
- AZ H. Familie Reet
- AZ Klina Brasschaat
- AZ Monica Deurne-Antwerpen
- AZ Sint-Augustinus Wilrijk
- AZ Sint-Elisabeth Herentals
- AZ Sint-Jozef Malle
- AZ Sint-Maarten Duffel-Mechelen
- AZ St-Dimpna Geel
- H. Hartziekenhuis Lier
- H. Hartziekenhuis Mol
- Imeldaziekenhuis Bonheiden
- Sint-Vicentiusziekenhuis Antwerpen-Mortsel
- Sint-Jozefkliniek Bornem Willebroek
- St. Elisabeth Turnhout
- St. Jozef Turnhout
- UZ Antwerpen
- ZNA Jan Palfijn Merksem
- ZNA Middelheim Antwerpen
- ZNA Stuivenberg – Sint-Erasmus Antwerpen

Brabant-Wallon
- Clinique Saint-Pierre Ottignies

Brussel / Bruxelles
- CHIREC Bruxelles – Autres sites
- CHU Brugmann Bruxelles
- Clinique Sainte-Anne – Saint-Remi Bruxelles
- Cliniques de l'Europe Bruxelles
- Hôpital Erasme Bruxelles
- Hôpital Universitaire Saint-Luc Bruxelles
- Institut Bordet Bruxelles
- Kliniek Sint-Jan Brussel
- UZ Brussel

Hainaut
- Centre de Santé des Fagnes Chimay
- Centre Hospitalier de Jolimont-Lobbes La Louvière
- CHR de la Haute Senne Mons (=Soignies)
- Clinique Notre Dame Tournai
- Clinique Notre-Dame de Grâce Gosselies
- CHU de Charleroi
- CHU de Tivoli La Louvière
- CHR clinique Saint-Joseph-Hôpital De Warquignies Mons
- Hôpital André Vésale Montigny-le-Tilleul
- Réseau Hospitalier de Médicine Sociale Baudour

Liège
- CHC Saint-Joseph Liège
- CH du Bois de l'Abbaye et de Hesbaye Seraing
- CH Peltzer-La Tourelle Verviers

Limburg
- CAZ Midden-Limburg Ziekenhuis Salvator – Sint-Ursula
- CAZ Midden-Limburg Ziekenhuis Sint-Franciskus
- Maria Ziekenhuis Noord-Limburg
- Regionaal Ziekenhuis Sint-Trudo Sint-Truiden
- Virga Jesse – Hasselt
- Ziekenhuis Oost-Limburg

Luxembourg
- I H Famenne Ardenne Condroz Aye

Namur
- Clinique Sainte-Elisabeth Namur
- Cliniques Universitaires de Mont-Godinne

Oost-Vlaanderen
- Algemeen Stedelijk Ziekenhuis Aalst
- AZ Jan Palfijn Gent
- AZ Maria Middelares Gent
- AZ Oudenaarde
- AZ Sint-Elisabeth Zottegem
- AZ Zusters Van Barmhartigheid Ronse
- OL Vrouwziekenhuis Aalst-Asse-Ninove
- Sint-Vicentiusziekenhuis Deinze
- UZ Gent

Vlaams-Brabant
- AZ Diest
- AZ Jan Portaels Vilvoorde
- Regionaal Ziekenhuis Heilig Hart Leuven
- Regionaal Ziekenhuis Heilig Hart Tienen
- UZ Leuven

West-Vlaanderen
- AZ Groeninge Kortrijk
- AZ Sint-Jan Brugge
- AZ Sint-Lucas Brugge
- Gezondheidszorg Oostkust
- H.-Hartziekenhuis Roeselare-Menen
- Henri Serruys Ziekenhuis AV Oostende
- OLV Lourdes Waregem
- Regionaal Ziekenhuis Jan Yperman Ieper
- Stedelijk Ziekenhuis Roeselare
- Sint-Andriesziekenhuis Tielt
- Sint-Augustinuskliniek Veurne
- Sint-Jozefskliniek Izegem

Table 4. List of participating hospitals, status on 01/02/2010

Urgent request to obtain relevant missing data

In search for better and more objective methods for benchmarking and feedback, the anonymised PROCARE databank will be used and tested in May 2010.

Knowing your results is essential. **Missing relevant data need to be reduced to a minimum**. Therefore, the PROCARE datamanagers did a major effort and sent you by the end of February 2010 an Excel file with the list of your registered patients asking to fill in missing relevant information. Additional information only was asked for those patients of whom it is missing in the database. Also, the number of requested data was limited to those related to disease free survival (i.e. local recurrence or metachronous metastasis), to essential data on (neo)adjuvant chemotherapy and to adjuvant radio(chemo)therapy for pStage II and III patients.

A reminder will be sent at the end of March and mid April 2010 if the additional information on your patients in the PROCARE database would not have reached the datamanagers by then.

No doubt, you will understand that this additional effort is needed for being able to give you better feedback with more objective and adapted benchmarking by the end of 2010.

At this occasion, but equally so at any time, your team can add forms of patients that have been treated but not yet registered. The more patients are registered, the better the quality of the feedback. Note that cStage IV i.e. patients with metastatic disease are an important part of the target patient population of the project. Their forms should also be submitted for registration.

Towards risk adjusted benchmarking in the PROCARE project

In the PROCARE project, a set of 41 quality of care indicators (QCI) for the management of rectal cancer has been identified. More than 130 variables per patient are prospectively registered. The ultimate goal of these major efforts is to improve clinical, multidisciplinary performance, i.e. outcome of the patients, by standardisation of staging, treatment and follow-up, and by detection and change in case of suboptimal performance. This goal can only be reached if the data are summarized and communicated in an appropriate way, including risk adjustment, control of data quality and evaluation of progress. Some colleagues may still be reluctant about audit. However, quality assessment of health care has become an essential, sometimes challenging aspect of clinical practice. Professionals should accept this challenge and take responsibilities, supported by methodological experts.

In his meeting of April 2009 the PROCARE Steering Group decided to collaborate with a group of statisticians and to submit a joint candidature for a study at the KCE on "Methods for benchmarking prospectively registered quality indicators of cancer treatment" what was done in May and accepted by the KCE.

The aims of this study are the following:

1. Which characteristics (risk factors) need to be taken into account to obtain a fair evaluation of the performance of individual teams (QCI) in the treatment of (rectal) cancer?
2. How can various outcome and process-related QCIs be combined?
3. How can a statistical approach based on mixed-model methodology provide a sound basis for such evaluation (also in 'low-volume' centers)?
4. Which quantifications should be the key elements in the feedback to the individual teams (position relative to other teams or to absolute quality standards; changes in performance over time)?

Presently, PROCARE offers feedback and benchmarking with reference to the median performance. More improvement is possible by referring to the 'best clinical practices'. Alternatively, targets can be predetermined by multidisciplinary peers. It is expected that with this new initiative an atmosphere of striving for optimal results will be created, based on confidential audit with risk-adjusted feedback. A scientific approach agreed upon by clinicians and statisticians is a prerequisite. The methodology will be tested on about 3000 patients registered in the PROCARE database. Evidently, the strict confidentiality rules, the multidisciplinary, decentralised, and educational nature of the PROCARE project will be respected.

With risk adjustment, feedback and benchmarking will not only be more credible but also more stringent. In case of suboptimal performance, teams will have to recognize the facts, plan and take actions with re-evaluation at a relatively short interval, provided by PROCARE.

Arrangements are being taken so that optimal feedback and benchmarking will continue after this study till the end of the project (and possibly beyond).

Text written by The PROCARE Steering Group

PROCARE Feedback

The feedback was given to the participating hospitals at the end of 2009. It was based on 2439 patients in total, distributed over 70 hospitals. In the new feedback report, a number of indicators were added, others were recalculated and the layout of the report was adapted to make it more coherent than the feedback of 2008.

You can find some key tables in Table 5, 6 and Figure 4 from the PROCARE feedback 2009. More information can be found on the website of the Belgian Cancer Registry.

A number of remarks are noteworthy. First, for some indicators we were confronted with a large number of missing data (for instance ASA, TME quality, dates of biopsy and radiotherapy, adjuvant chemotherapy). Second, there are still some problems with the use of the report sheet; some teams still use a dated version of the report sheet, others create their own sheet, without including all necessary information. Therefore, we suggest in the future to use the online application, or - at least - use the most recent version of the PROCARE data entry form (new version since 01/01/2010 can be found on the website of the Belgian Cancer Registry). Finally, from 2010 on, we are aiming at giving feedback twice a year, one intermediate short feedback in the middle of the year (June-July) and one complete feedback at the end of the year (December). More information can be found on the website of the Belgian Cancer Registry.

Technique of resection	Frequency	Percent	Cumulative Frequency	Cumulative Percent
PME	342	14,0	342	14,0
TME	1793	73,5	2135	87,5
Conventional	22	0,9	2157	88,4
Missing	282	11,6	2439	100,0

Table 5. Overview of the techniques used for resection

Type of reconstruction	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Polypectomy	1	0,04	1	0,04
Local excision	12	0,49	13	0,53
TEM	16	0,66	29	1,19
APER	432	17,71	461	18,90
Hartmann	62	2,54	523	21,44
HAR + CRA	53	2,17	576	23,62
LAR + CRA	423	17,34	999	40,96
TME + straight	412	16,89	1411	57,85
TME + Pouch	477	19,56	1888	77,41
TME + Coloplasty	42	1,72	1930	79,13
TME + Other	242	9,92	2172	89,05
Other techniques	14	0,57	2186	89,63
Missing	253	10,37	2439	100,00

Table 6. Overview of the types of reconstruction

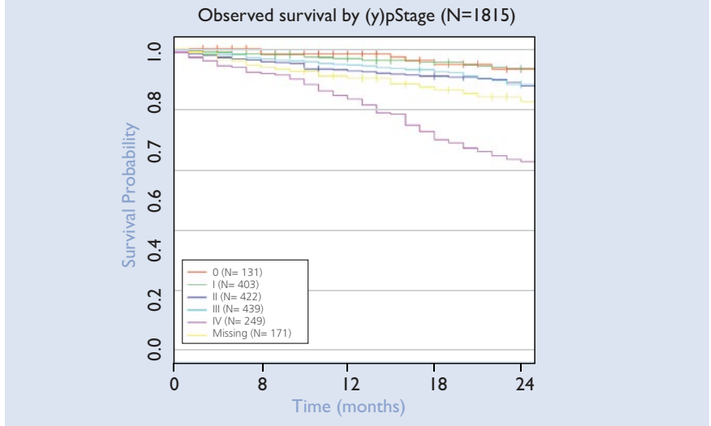

Figure 4. Overall overview of the observed 2 year survival (Kaplan-Meyer Curve)

PROCARE web

The PROCARE web application is currently in its final test phase. In the future, online registration will be the preferred means of registration. It is expected that the PROCARE web application will be operational at the beginning of 2010. In order to use it, you will need to possess a token or an eID (electronic Belgian ID card) together with its reader and its pin. We can help you with the procedure of obtaining an eID card reader. We will also provide you with a user manual in which all the steps about 'how to use the application' are explained. The manual and more information will be found at the website of the Belgian Cancer Registry.

In order to receive access to the PROCARE web application, a personal user account has to be created. The system of 'Lokale Beheerders (LB)—Gestionnaires Locaux (GL)' by eHealth is widespread through Belgian hospitals and will be used. The LB – GL can give access to persons who will use the online application.

The use of the PROCARE web application will ask some efforts. On the other hand, a number of benefits, compared to the paper version, will be offered. First, every specialist will have the opportunity to fill in the chapter of his or her speciality. The status of each chapter will be visible for every specialist who is involved to this specific registration form. The usability of the application will support the multidisciplinary character of the PROCARE project. There will be a distinct overview of all cases registered thanks to the use of a work list. Second, data are transferred directly to the Belgian Cancer Registry, which makes the transfer easy and safe. Third, it will be more difficult to make mistakes when filling out the registration form, due to the limitation in answering options, often defined by previous answers. This will result in a database with a higher quality of data and consequently with more reliable results.

Some screens of the PROCARE web application are shown in figure 5, 6 and 7.

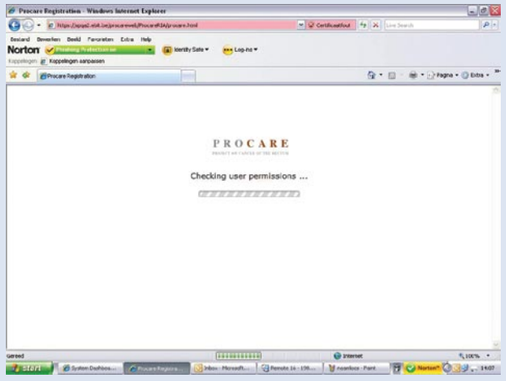

Figure 5. When logging-in to PROCARE web, the user-permissions will be checked.

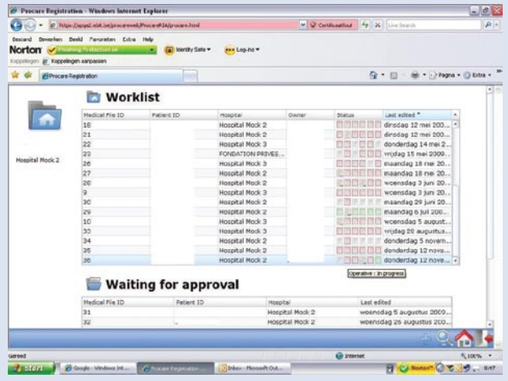

Figure 6. Homescreen, view from the Responsible Specialist.

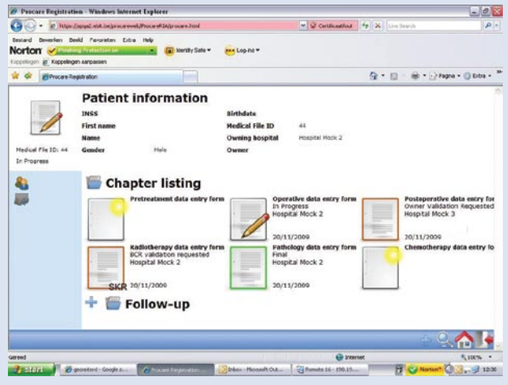

Figure 7. The registration form consists of 6 different chapters plus follow-up.

PROCARE RX online application

PROCARE RX will make it possible for the radiologists to ask for an anonymous second opinion on cTN and cCRM, based on CT-scan and MRI-images of the pelvis. The PROCARE RX application is the first of its kind in Belgium. It will be a unique project which can be very useful for every radiologist who wants a second and anonymous opinion of CT- and/or MRI-images. In case of discordance between the local radiologist and the expert radiologist, a second review will occur. The process stops here, no third review will be possible.

A team of expert radiologists was indicated by the Royal Belgian Society of Radiology. They will review these images at random and in an anonymous way to assess quality and reliability of the interpretation.

The PROCARE RX online application will be operational in the beginning of 2010. Security and web accessibility issues are identical for both the PROCARE web application and the PROCARE RX online application: the system of 'Lokale Beheerders (LB)—Gestionnaires Locaux (GL)' by eHealth will create the access to the platform.

Some opening screens of the PROCARE RX application are shown in figure 8, 9 and 10.

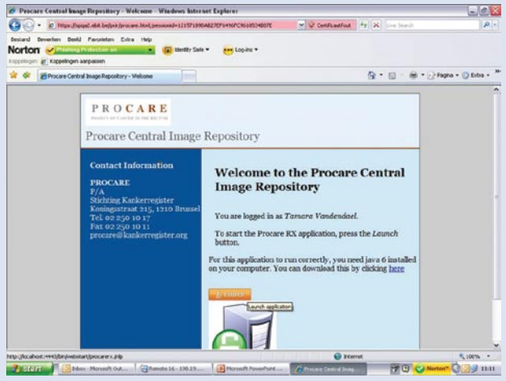

Figure 8. When choosing your profile, your permissions will be checked.

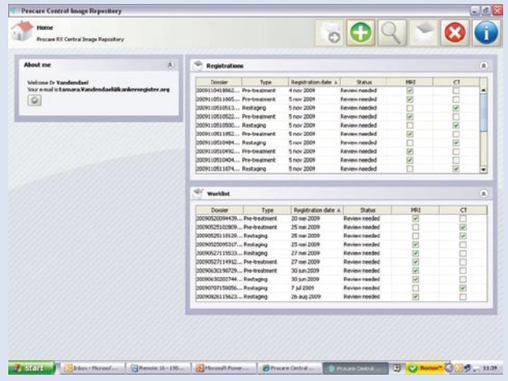

Figure 9. Homescreen, point of view from Expert Radiologist/ Reviewer.

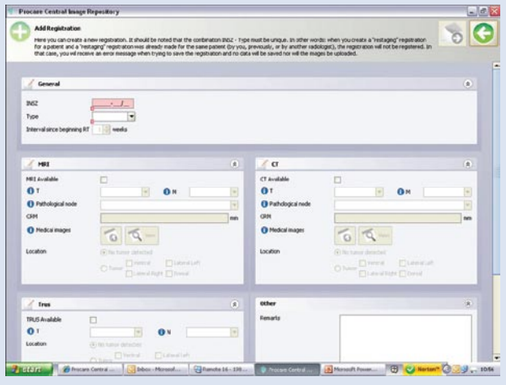

Figure 10. Worksheet when asking for a second anonymous opinion.

PROCARE Highlights

New PROCARE Registration form

The new PROCARE registration form will be used for cases submitted since 1st January 2010 (prospective and retrospective registration). The updated version can be found on the website of the Belgian Cancer Registry.

Request for missing data – follow-up

Requests for missing data were sent at the beginning of 2010 individually per center. These are mostly but not only chemotherapy, radiotherapy and follow-up forms. We kindly ask you to send the missing parts for your registered patients in case you have not yet done so. Thank you for your efforts.

Feedback to pathologists

We are in the process of organizing individual feedback to the pathologists based on the pathological material, checklists and reports received. This will be sent out individually in the course of the following months.

Radiotherapy

An online communication platform (AQUILAB software) will be created between the departments of Radiation Oncology. The purpose is to exchange "contours" delineated on the dosimetric CT scan and to perform a central review. In that way, the target volume of pre-operative irradiation will be homogenized by comparing the volumes proposed by each hospital to a central atlas.

Attendance to congresses

PROCARE was represented at the Belgian Week of Gastroenterology (February 2009, Antwerp) and at the Belgian Surgical Week (April 2009, Oostende). We look forward to represent PROCARE again in 2010.

Please send us all your remarks and comments! We are always ready to help you.

Tamara Vandendael and Koen Beirens are working at the BCR for PROCARE.

PROCARE
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Stichting Kankerregister
Registre du Cancer

Koningsstraat / Rue Royale 215
1210 BRUSSEL / BRUXELLES
België / Belgique
Tel. +32 (0)2 250 10 17
Fax +32 (0)2 250 10 11

procare2@kankerregister.org
procare2@registreducancer.org

www.kankerregister.org,
submenu PROCARE

www.registreducancer.org,
submenu PROCARE

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INAMI RIZIV