

Newsletter October 2006.

Seizing an opportunity ...

Dear colleagues,

The PROCARE project started in the winter of 2004 with the aim to improve the quality of rectal cancer care in Belgium. Indeed, at that time the benefit of several national projects/studies in other European countries (Sweden, the Netherlands, Norway, Denmark, ...) had just been published.

All medical specialties involved in the care of rectal cancer established a multidisciplinary working group in which they are represented by delegates from the respective scientific societies. Delegates from the Belgian Professional Association were included as well from the start as it was evident that the project should not only have a scientific backbone, but should be driven by 'the professionals'.

First of all, multidisciplinary guidelines on the management of rectal cancer were discussed and a first draft was written. This first version of the PROCARE Guidelines was made available by the respective scientific societies. I hope all of you could download them. In the context of a study assigned by the KCE to PROCARE (summer 2006) and related to the identification of quality of care indicators, the guidelines will be upgraded to an international standard in the coming months.

Through this all, it is evident that a unique opportunity has been created for all the professionals involved in the care of rectal cancer patients to put into practice their willingness to improve the quality of care for their rectal cancer patients and to show it to the 'others', incl. the patients.

To be feasible, the project not only requires an effort of all of you, but also a lot of money. The search for financial support from the authorities has been the major activity of the PROCARE working group in 2006. They succeeded. The project has financial support from the Stichting tegen Kanker, Fondation Contre le Cancer, and from the KCE (Kennis Centrum/Centre d'expertise), and from the RIZIV/INAMI (KB/AR to be published soon).

Central registration of 'credible' and high-quality data is a key issue in a national project like this. Fortunately, PROCARE found an excellent 'partner' at the Belgian Cancer Registry. The work done there and the enthusiasm shown are really exemplary.

Of course, the database would remain empty without your input. Until now, mainly surgeons have submitted data. Roughly, about 23% of resectable rectal cancer patients (approx. 1200/year in Belgium) are registered. If you would reach 33% by the end of the year, it would be marvellous and comparable with what was achieved in other countries. May I remind that all patients with rectal cancer should be submitted for registration, including those with inoperable rectal cancer, those who have palliative (surgical or non-surgical) treatment.

Behaving as a 'professional' has changed a lot in the last decade. This change is excellently summarized in a paper of the American Gastroenterology Association (AGA Task Force on quality in practice: a national overview and implications for GI practice. *Gastroenterology* 2005; 129: 361-369). It is concluded that "the rapidly growing nationwide focus on patient safety and quality of care measurement, documentation, and reporting mandates proactive involvement of specialty societies in defining quality and developing and implementing meaningful and quantifiable measures of quality in clinical practice. If we do not do so, the purchasers and users of our services will define both how medicine should be practiced and our value." Of course, this does not only apply for gastroenterologists! I strongly recommend this paper to all of you, in particular those who are not yet fully convinced that professional participation in quality of care has become a necessity.

In this context, I warmly and urgently invite all teams to join the PROCARE project and to register all patients with rectal cancer at the Belgian Cancer Registry. The magnitude of your practice is not relevant. The concept of a national project, indeed, should and does not allow exclusion of anybody or any team involved. Finally, if you would be interested in some of the scientific or organizational aspects of the project, you would be more than welcome. On behalf of the working group, I thank all those who are investing a lot of their 'free time' in the project, and have done so in the past. The success of the project will be the merit of the Belgian medical professionals! Seize the opportunity.

Freddy Penninckx, chairman of the PROCARE working group.
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RIZIV / INAMI support.

Basically PROCARE is a profession – driven quality improvement program based on registration, individual feedback and education. The estimated cost for the project is somewhere around 1.5 million € for the first 5 years. The full development of this initiative would not be possible without substantial support from the Health Authorities. As stated before, the PROCARE workgroup has been involved in quite intensive and finally successful negotiations on financial support.

Indeed, PROCARE will get financial support as a national experiment to improve the quality of Healthcare in Belgium. A KB / AR *“setting the conditions for financial support to a temporary and experimental project to improve the diagnosis and treatment of rectal cancer”* was submitted to the Verzekeringscomité / Comité d'Assurance by the health administration and it was unanimously approved by the Committee on July the 24th.

Through this KB / AR €1.275.000 will be committed to the project as a whole and an additional €142.500 for the development of the registry and its (multi-usable) modules. As soon as the KB / AR on PROCARE is published in the “Belgisch Staatsblad / Moniteur Belge” the PROCARE staff will be able to make the necessary investments for electronic registration, data analysis and feedback. Hopefully the electronic backbone of PROCARE will be made operational by the beginning of 2007. For those who started registration during 2006, a personal feedback will be available soon after.

This does not mean that meanwhile nothing has been done as far as rectal cancer registration is concerned. Further in this newsletter additional information is given on the state of affairs of the registry and the work done at the Belgian Cancer Registry (BCR) on behalf of PROCARE.

A spin off of PROCARE: KCE study on Quality of Care Indicators.

The KCE (Kenniscentrum / Centre d'Excellence, director Prof. Dr. D. Ramaekers) was set up to improve the quality of health care in Belgium based on sound scientific evidence. Within the framework of its mission the development of quality of care indicators is of paramount importance. Since it is appreciated that this cannot be done effectively and trustworthily without significant input from clinicians, the PROCARE Workgroup was selected to participate in its study on quality of care indicators for rectal cancer.

The study entails five steps:

- Validation of Belgian Guidelines (CEBAM) based on the available evidence in national and international literature, defining the level of evidence, level of consensus and level of recommendation for the statements in the Belgian Guidelines.
- Search on validated and consistent quality of care indicators in the international literature.
- Evaluation of the existing Belgian databases and definition of data missing in order to set up a framework for quality evaluation and improvement.
- Recommendations on making the data needed available and on their interpretation and usage taking into account the necessity of risk adjustment as well as the reliability and the consistency of the data.
- Make recommendations on the use of these data to achieve effective quality improvement.

You will appreciate that an active involvement of the profession is absolutely needed for such an endeavour but is at the same time a unique opportunity offered to us by the KCE in times when all too often managers and analysts without any clinical experience and judgement aim to define the standards of care. Indeed the first analyses done once again stress the importance and necessity of complete clinical data provided and evaluated by the medical professionals involved in order to avoid rash judgements and unfair conclusions.

On the KCE side Dr. J. Vlayen is responsible for the project.

The PROCARE task force consists of: D. Claeys, D. De Coninck, N. Ectors, K. Haustermans, D. Léonard, M. Peeters, F. Penninckx, M. Polus, E. Van Cutsem and E. Van Eycken.

Rectal Cancer Registry: state of affairs.

Participation in the registry

As of October the 20th some 31 centers representing 41 surgeons actively participated by sending in their cases. Of those 41 surgeons 21 are candidate trainers. A total of 303 cases have been sent in.

There is a strong difference between participation in the North and the South of the country: 33 Flemish surgeons send in their cases (16 of them candidate trainers) versus 8 French speaking surgeons (5 of them candidate trainers). This includes the hospitals from Brussels. The geographical spread can be exemplified on a map of the country (see figure 1).

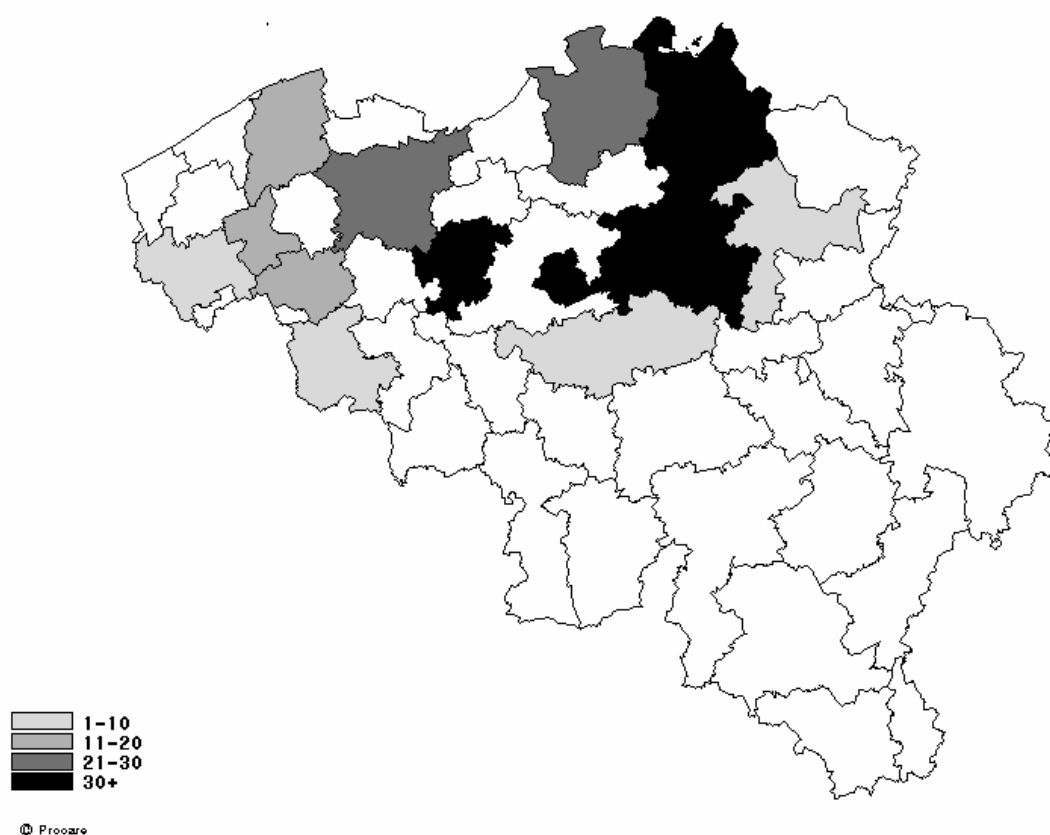


Figure 1: PROCARE participation per district.

The rate of participation is very encouraging in the Northern part of the country but a lot of work remains to be done in the South. Once again it has to be reminded how important participation of as many centres as possible is for the future, in particular of smaller centres.

Data handling at the BCR...

As stated before, for the time being, only the cases of the candidate trainers are digitally processed in view of evaluation. This work is done by the BCR on its own means. In fact at the BCR very recently a Flemish speaking 1 FTE data manager, 0.6 FTE French speaking data manager and an additional 0.2 FTE from the EUROCHIP-II project are working on the set up of PROCARE. Through a financial support from the Foundation against Cancer (Stichting tegen Kanker – Fondation contre le Cancer) one full time data manager at the BCR is granted on the project for three years. This person works on the nationwide and multidisciplinary data acquisition, surveillance and audit with feedback to the physicians.

As soon as the government subsidy is granted (hopefully in the coming weeks) the PROCARE related activities at the cancer registry will come to full throttle and all cases that were sent in (including those from non candidate trainers) will be processed in the electronic database and the feedback system will be set up.

For registration of new patients (data entry forms etc), please contact one of the following data managers at the Foundation Belgian Cancer Registry: Mrs. Huysegoms Mara (Dutch and French) at procare2@kankerregister.org and Mrs. Rachel Gengoux (mainly for French speaking colleagues) Rachel.Gengoux@kankerregister.org. No doubt, they will be of great help to you. Please let them know if they could be at any assistance to fill in the data entries for you.

Lessons learned...

Meanwhile some lessons can be learned from the analysis of the records of the candidate trainers.

Six candidate trainers already sent in 10 or more consecutive cases amounting to a total of 63 cases which are reviewed by both the pathology and the surgery evaluation committee. Were deemed good: 28 cases, deemed insufficient 10 cases but strikingly deemed non evaluable: 25 cases which actually means almost 40%.

Noteworthy is that of those 25 non evaluable cases, 10 cases were Partial Mesorectal Excision (PME) and not TME cases. They cannot be taken into account for evaluation of the candidate trainers since the evaluation is on the quality of the TME procedures. The other 15 non evaluable cases can be explained by a shortage of pathology material. Thus there definitely seem to be remaining problems with pathology and in fact questions about pathology are leading the list of FAQ's at the BCR. A mailing with the current guidelines will shortly be sent to all pathologists by the 'Digestive Club of Pathologists' in order to answer these specific questions. They relate on the handling of the specimen (macroscopic aspect, slices), criteria for evaluation of the specimen, pathology guidelines, the fate of PME specimens in the evaluation process (*in fact they are not taken into account for TME evaluation*) and which cases of rectal cancer have to be submitted (*in fact all of them*).

Therefore the Board of the BSCS held on the 25th of September decided to send a first individual feedback to all candidate trainers in the coming weeks. Besides from letting them know where they stand, it will also give them an insight on how evaluation works and an opportunity to adjust their registrations to the needs of evaluation.

The Board also decided that in the first half of 2007 a national meeting should be held to communicate the state of affairs (participation, problems met, first results...) to the surgical community.

Obviously all communication and feedback will be done with respect of the pledge of anonymity given to the participating centres. All feedback will be given by the BCR on an individual basis.

Pathology.

As already mentioned, the FAQ's at the cancer registry mainly concern pathology. From this it is obvious that a large number of pathologists are aware and willing to participate. In the mean time the peers revised an important number of resection specimens allowing us to draw some conclusions. First, it is mandatory that pathologists take photographs to allow 1) evaluation of the quality of surgery, and 2) assessment of the candidate trainers. Second, all rectal cancer cases have to be included by the pathologists – independently of the treatment i.e. stage. Third, additional information needs to be circulated on certain practical aspects e.g. photographs or pathological topics e.g. grading of regression. Therefore all pathologists will receive by mail an updating on the PROCARE project concerning all these issues. Moreover during the Winter Meeting of the SBAP - November 18th 2006, Campus of the Erasme Hospital – all these issues will be addressed in an invited lecture.

Radiotherapy.

The colleagues from Radiation Oncology are in the process of selecting a quality assurance platform which will be used to review target delineation and isodose distributions from the patients treated with radiation in the PROCARE project. In the meantime the atlas for target delineation has been published in the Int J Rad Onc Biol Phys, July issue.

International Benchmarking.

Several European countries started a Rectal Cancer Registry analogous to the one being set up in Belgium. Contacts are actively pursued between them in order to set up a European Register and to explore the possibilities of European benchmarking.

The PROCARE guidelines (first draft) can be downloaded from
www.belsurg.org/imgupload/BSCRS_/PROCARE%20GUIDELINES%20printversie82005.pdf