

## Current role and future perspectives of the Belgian Cancer Registry in quality of cancer care projects

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The Belgian Cancer Registry, just like other population based cancer registries, sees its role more and more extended to cancer control. Besides pure descriptive tasks such as reporting on cancer incidence and survival, it also gets involved in projects on quality of care. The main and general objective is to improve the outcome and quality of cancer treatment. Registration takes into account prognostic variables and allows individual feedback on process and outcome indicators.

The Cancer Registry offers a source of expertise in the techniques of sampling, abstracting, data management, analysis and interpretation of results in collaboration with clinical experts. Joined forces between clinicians, researchers, epidemiologists and cancer registration experts can lead to well conducted studies on quality of cancer care in Belgium. The national and multidisciplinary project on cancer of the rectum, Procure, is a well known example of a bottom-up driven approach.

This article gives an overview of the actually ongoing projects in the context of quality of cancer care and describes the possible use of data for future research.

*(Belg J Med Oncol 2010;4:216-22)*

### Introduction

New legislation initiatives since 2003 and the foundation of a new National Registry in 2005 by all Belgian authorities involved in public health, forced a breakthrough in the Belgian cancer registration.

Especially the royal decree on the oncological care programs in 2003 with the reimbursement of the multidisciplinary oncological consultations and the creation of the specific law on the Cancer Registry in 2006 provided a firm legal basis for cancer registration in Belgium.<sup>1,2</sup> This legislation makes cancer registration compulsory for the oncological care programs and authorizes to the Belgian Cancer

Registry the use of the national social security number (INSZ/NISS) as the unique identifier of the patient. The use of this unique number also creates perspectives for linkage with other available medical and/or administrative data. It must be clear that such a linkage not only requires the authorization of the Privacy Commission but also implies severe measures and rules for privacy protection and confidentiality.

The first goal of the new Belgian Cancer Registry was to achieve completeness in cancer registration for the whole country which was obtained for incidence data from the year 2004 onwards.<sup>3</sup> On the one hand,

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**Conflict of interest:** the authors have nothing to disclose and indicate no potential conflicts of interest.

**Key words:** cancer registration, epidemiology, outcome and process indicators, quality of cancer care

the data flow relies on clinical information from the oncological care programs. On the other hand, the pathological anatomy laboratories and hematology departments supply the Belgian Cancer Registry with their data. The most recent cancer incidence data (2006) are published on the website of the Belgian Cancer Registry.<sup>4</sup> Data of the incidence year 2007 and 2008 are expected to be officially released by the end of 2010. Time between registration and availability of incidence data must indeed be kept as short as possible to have a good reflection of the actual situation. But the Cancer Registry produces more than only data and figures.

The Belgian Cancer Registry just like other population based cancer registries sees its role more and more extended to cancer control.<sup>5</sup> Starting with pure descriptive tasks such as reporting on cancer incidence, it also gets involved in projects on quality of care.<sup>6</sup>

Quality of care can be defined as providing patients with appropriate services in a technically competent manner, with good communication, shared decision-making and cultural sensitivity.<sup>7,8</sup>

This article gives an overview of the actually ongoing projects in the context of quality of cancer care and describes the possible use of data for future research.

## Survival

Survival rates are often regarded as important and general outcome indicators in the evaluation of care. The Cancer Registry has a legal authorization to link its patient data based on the national number with the vital status of the patient and the possible date of death, available at the National Registry.

In many cases the cause of death of cancer patients is unknown, inaccurate or simply unavailable for the Cancer Registry. Consequently, it is not possible to calculate disease-specific survival. In this respect, the Cancer Registry actually examines the possibilities with the relevant authorities to link the data with the mortality data (death statistics).

However, relative survival forms a good approach to disease-specific survival and is thus a frequently used parameter in cancer epidemiology.<sup>9</sup> The relative survival rates reflect an estimate of the expected survival of cancer patients, in which causes of death other than cancer have been left aside. Data on

5-year relative survival were published for the first time in 2006 for the Flemish region.<sup>10</sup> Five-year observed and relative survival rates for some selected tumour sites are presented in *Table 1*. As expected, primary tumour localisation, histological type and stage at diagnosis were important prognostic factors. The available data enabled comparisons with other European countries/regions in the Eurocare-4 study.<sup>11</sup>

The objective of the Cancer Registry for 2010 is to update the 5-year relative survival to a 10-year relative survival rate for the Flemish region and to extend the survival rates to Belgium (inclusion of the Brussels and the Walloon region). The descriptive study will be guided and supervised by the Scientific Committee of the Cancer Registry and a specific multidisciplinary working group of experts.<sup>12</sup>

## Quality of care - quality indicators

When compared to clinical studies, population based registries have the advantage to present more general results on 'all' cancer patients treated (no selection bias, e.g. also on the elderly). On the other hand, clinical studies/medical files contain more detailed information on diagnostic, prognostic and treatment related aspects.

Quality of care studies with registration of this supplementary information carried out in close collaboration between clinicians and the Cancer Registry can remove or at least reduce the disadvantages or biases from both sources separately. Three methodologies are possible:

1. Additional information can be obtained in administrative data bases such as the hospital discharge data (MKG-RCM) and the nomenclature data of the Health Insurances/RIZIV-INAMI. Linkage of cancer registry data with nomenclature or hospital discharge data certainly reduces the administrative work load of the physician or his data manager. A very cautious interpretation of the results must be done because of previous financial implications of these data. Moreover, in the nomenclature data base itself, the medical acts are often not specific enough and are not related to a listed diagnosis. Cautious linkage with cancer registration data is needed with expert intervention to resolve linkage uncertainties.

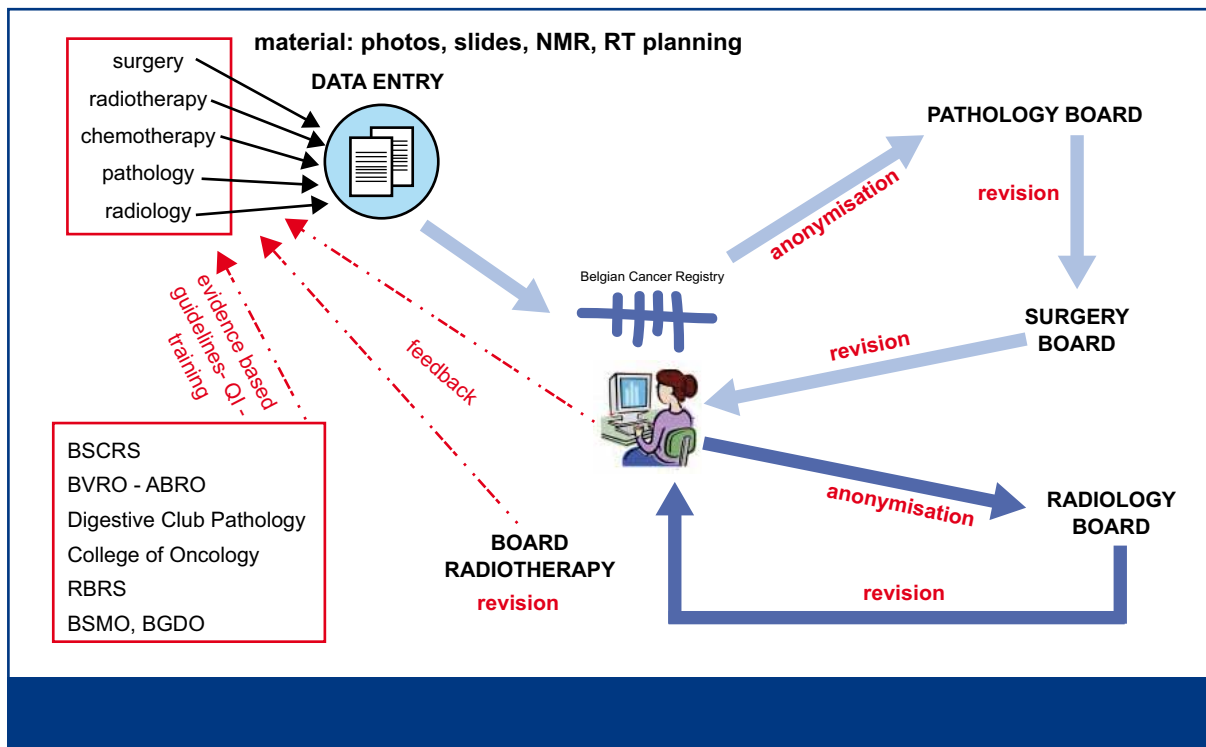
**Table 1.** Males and females, some selected invasive tumours: 5-year observed survival and 5-year relative survival for tumours diagnosed between 1997 and 2001 in the Flemish Region.

Males	5-year observed survival (%)	5-year relative survival (%)
Larynx	52	60
Oesophagus	17	19
Colon and rectum total	46	57
stage I	71	88
stage II	58	73
stage III	44	53
stage IV	8	10
Lung	12	14
Prostate	68	85
Bladder	48	60
Testis	93	95
Brain (all ages and types included)	25	26
Low grade astrocytoma (0-14 years)	87	
High grade astrocytoma (0-14 years)	44	
Diffuse non-Hodgkin lymphoma	51	58
Melanoma total	62	69
stage I	87	94
stage II	61	70
stage III	46	54
stage IV	9	10
Thyroid gland	71	77

Females	5-year observed survival (%)	5-year relative survival (%)
Larynx	57	62
Oesophagus	19	22
Colon and rectum total	47	57
stage I	77	91
stage II	59	72
stage III	42	50
stage IV	8	9
Lung	18	20
Breast	75	82
Bladder	44	54
Corpus uteri	70	78
Brain (all ages and types included)	28	29
Diffuse Non- Hodgkin lymphoma	48	54
Melanoma total	74	80
stage I	87	92
stage II	75	82
stage III	42	48
stage IV	19	20
Thyroid gland	74	77

2. The second possibility is a prospective registration project which is far more labor intensive for the physicians and the Cancer Registry, but it offers the possibility to gain detailed information and

insight on process versus outcome and structural indicators. Extensive feedback to the individual clinician and/or hospital may be experienced as an incentive or compensation for the registration



**Figure 1.** Procure: data flow. NMR=nuclear magnetic resonance, RT=radiotherapy, QI=quality indicators, BSCRS=Belgian Section for Colorectal Surgery, BVRO-ABRO=Belgische Vereniging voor Radiotherapie-Oncologie; Association Belge de Radiothérapie-Oncologie, RBRS=Royal Belgian Society of Radiology, BSMO=Belgian Society of Medical Oncology, BGDO=Belgian Group of Digestive Oncology

work delivered. Limited participation of the hospitals/clinicians (selection bias) and a lack of exhaustiveness of registration data (quality of data) are the weaknesses and pitfalls of this methodology.

### 3. A mixture of the first and the second solution.

Ideally, quality of care projects are launched and conducted in a bottom-up approach i.e. by motivated physician experts delegated by their scientific or professional associations. Quality of care studies are ideally carried out when there is potential for improvement or prevention of deterioration. A close collaboration between physicians and the Cancer Registry is a prerequisite for success. The Cancer Registry forms an ideal platform for this kind of projects because of its daily practices in registration, data quality control, linkage and analysis. Indeed, the Registry offers a source of expertise in the techniques of sampling, abstracting, data management, analysis and interpretation of results.<sup>13</sup> It is essential that the Cancer Registry

handles strict criteria for confidentiality in order to maintain a trusting relationship between the physicians and the Registry.

In contrast to a bottom-up approach, a top-down initiative in quality of care i.e. initiated by the authorities often induces the fear of physicians of moving towards an obligatory and by law centralized care.

### Some examples of ongoing projects at the Belgian Cancer Registry in collaboration with clinical scientific societies

#### Procure

Meanwhile, Procure has become a well known national and multidisciplinary project on cancer of the rectum. The project is an example of a bottom-up approach. The Procure board takes the lead of the program and is composed of all disciplines involved in the diagnosis and/or treatment of rectal cancer and delegates from the Cancer Registry. Members

of the board represent their scientific organizations and are equally distributed between academic and non-academic hospitals, and French and Dutch speaking physicians. The project is financed by the RIZIV-INAMI (2008-2012) and the 'Stichting tegen Kanker – Fondation contre le Cancer' (2006-2007). The overall objective of this project is to improve the outcome of rectal cancer patients.<sup>14</sup> Several components of the project help to achieve this goal (Figure 1).

Evidence based guidelines were developed and published in collaboration with the Belgian Health Care Knowledge Centre.<sup>15</sup>

The organization of training and the educational programmes also tend to improve uniformity in diagnosis and treatment.

In addition, quality indicators were derived from the guidelines and used to create feedback to the multidisciplinary teams. An example of a quality indicator is given in Figure 2.<sup>15</sup> The graph represents the percentage and the 95% confidence interval of non-sphincter sparing surgical procedures per hospital. Figure 3 describes the observed 2-year survival of the patients included in the Procure study.

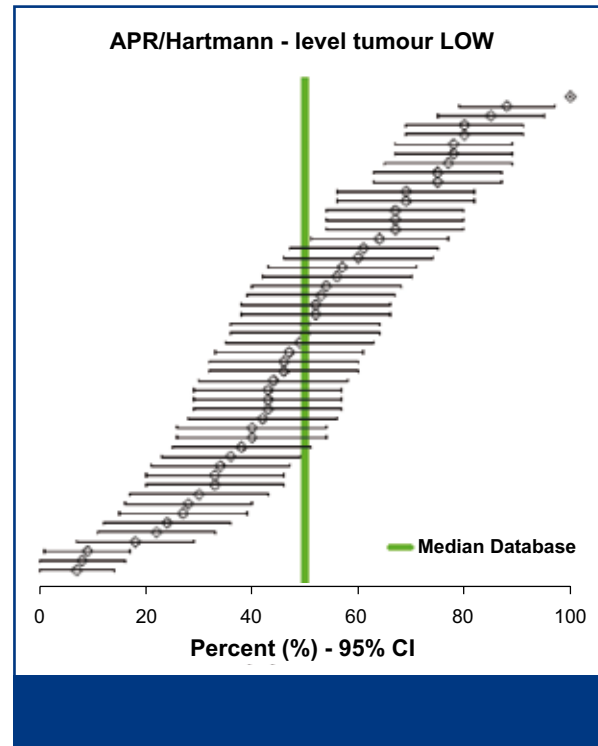
Moreover, prospective registration and anonymous revision of different aspects on diagnosis and treatment are the pillars of the study. Revision of the quality of the total mesorectal excision (TME) specimen, the pathology report, the results of the pelvic nuclear magnetic resonance (NMR) scan and radiotherapy treatment planning is carried out by expert surgeons, pathologists, radiologists and radiation oncologists.<sup>16</sup>

The Cancer Registry takes care of the data handling, data validation, data storage, data anonimisation and the feedback to the clinicians. The Cancer Registry also provides support for further in depth studies on the Procure data.

#### *Project on cancer of the oropharynx*

The registration project on cancer of the oropharynx has been set up by the Flemish Working Group on Head and Neck tumours (VWHHT) in collaboration with the Cancer Registry. It will soon be extended to a national level.

Cancer of the oropharynx is a rare disease; about 500 new cases are registered in Belgium every



**Figure 2.** Percentage of non-sphincter sparing surgical procedures (abdominoperineal resection and Hartmann's procedure) for cancers of the lower third of the rectum (total N=401) per hospital. Only hospitals with 10 or more rectal cancer cases in the Procure study are included.

year.<sup>3</sup> Evaluation of the treatments used in different centers by the working group revealed a large variability in treatment strategies (communication on the VWHHT congress 6<sup>th</sup> of December 2008 by Professor Vincent Vander Poorten).

The first goal of the working group was to set up the prospective registration, to describe and reduce the variability of treatment for this rare cancer and to follow up on outcome. Prognostic variables, risk factors and data related to the treatment are registered in a protected online registration application of the Cancer Registry. The online registration of oropharynx tumours was launched in August 2009. At the VWHHT meeting in Brussels on March 13, 2010, the first results about the participation were communicated to the group.

An individual feedback on process and outcome indicators will be provided to the participating centers. The registration project can also be considered as a pilot project or feasibility study to evaluate the possibility of future registration projects

for head and neck cancers.

#### *Project on brachytherapy of prostate cancer*

The project 'brachytherapy of prostate cancer' was launched in 2005 by the College of Physicians Radiation Oncologists, the Belgian Association of Urologists (BAU) and the Multidisciplinary Brachytherapy Working Group. Collaboration was initiated in 2008 with the Cancer Registry: paper registration was left in favour of the online registration module of the Cancer Registry. The objective is to evaluate the quality of the radioactive iodine implant by measuring process and outcome indicators. The indicators are defined by the experts of the Brachytherapy Working Group and are related or derived from international guidelines.

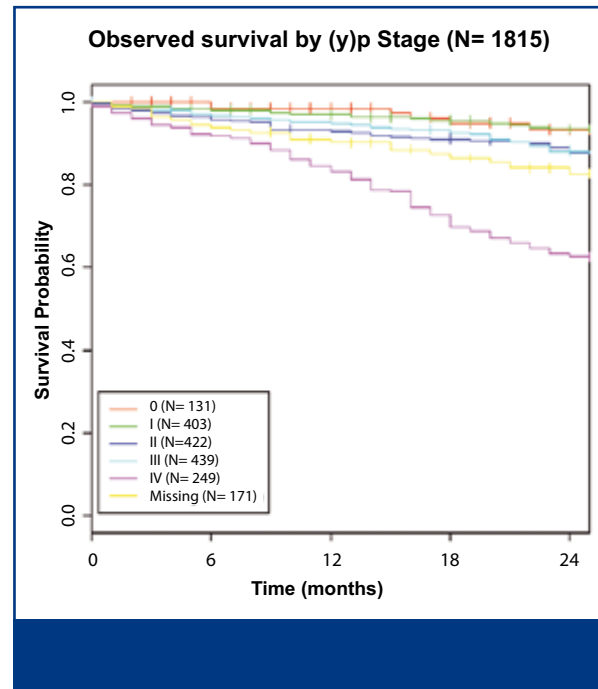
The first descriptive results were communicated at the BAU congress on December 11, 2009 after validation by the Brachytherapy Working Group. Individual feedback is sent to the individual participating centers.

#### *Project on haematologic malignancies*

A project on prognostic factors in haematologic tumours is ongoing, a collaboration has been set up with the Belgian Haematology Society (BHS). Haematological tumours differ in many aspects from solid tumours and need a specific approach for registration. Developments in immunophenotypic and molecular biological techniques have brought new insights and have completely changed the classification of leukemias and lymphomas. Non Hodgkin lymphoma, leukemia, multiple myeloma, myelodysplasia and chronic myeloproliferative diseases are included in the project. The goals of the study are quite similar with those mentioned above in the two projects. This registration project aims to study on prognostic factors and to compare outcome taking into account morphologic, immunophenotypic and genetic information. An individual feedback will be provided to the participating centers.

## Conclusion

Quality of care studies should result in optimizing treatment strategies and reducing variability in treatment. Follow-up on outcome, feedback to the clinicians and the comparison of prognostic factors



**Figure 3.** Procure: 2-year observed survival of rectal cancer by pathological stage (pStage) or pathological stage after initial neoadjuvant treatment (ypStage) (Kaplan Meier method).

ultimately should lead to an improvement of the prognosis in patients.

Several ongoing projects on quality of care are carried out in collaboration between the Cancer Registry and Scientific Physician Organizations. They mostly focus on process and outcome parameters. Future projects should also concentrate on health care costs, on assessment of structure which reflects the provision of care and on health-related quality of life assessment in oncology practice. The Cancer Registry also hopes to collaborate in international collaborative projects on cancer care.

Joined forces between the clinicians and epidemiologists and cancer registration experts and a trusting relationship can lead to well conducted research on quality of cancer care in Belgium.

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## Key messages for clinical practice

- 1. New legislation initiatives since 2003 and the foundation of a new National Cancer Registry in 2005 by all Belgian authorities involved in public health, forced a breakthrough in the Belgian cancer registration.**
- 2. Besides pure descriptive tasks such as reporting on cancer incidence and survival, the Cancer Registry also gets involved in projects on quality of care. A well known example is Procure, a national and multidisciplinary project on rectal cancer.**
- 3. The Cancer Registry offers a source of expertise in the techniques of sampling, abstracting, data management, analysis and interpretation of results in collaboration with clinicians and other experts or organizations.**
- 4. Joined forces between the clinicians, epidemiologists, research organizations and cancer registration experts within a trusting relationship can lead to well conducted research on quality of cancer care in Belgium.**

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