Exchange of data between a Comprehensive Cancer Centre and the Belgian Cancer Registry: a single university institution experience

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The main goals of hospital-based and population-based cancer registries are respectively to contribute to patient care by providing information on cancer patients and to produce statistics on the occurrence of cancer in a defined population in order to assess and monitor the impact of cancer in the community. To achieve these goals the use of complete quality data is essential. Therefore, cooperation between a hospital-based cancer registry (HBCR) and the Belgian Cancer Registry (BCR) was set up. A pilot study was conducted to exchange clinical data (date of death) between the HBCR and the BCR. Secondly, we wanted to analyse the completeness and the quality of data delivered by the HBCR to the BCR.
For the pilot study, all new patients with a diagnosis of head and neck cancer in 2005 and 2006 were included. For the analysis of the completeness and quality of the data all invasive or in situ cancers with an incidence date of respectively 2005 and 2006 were included.
The HBCR could be supplemented with 23 dates of death (42%). Overall, the completeness of the registration was near 100%. Except for the TNM-data of malignant melanoma the quality of the data delivered by the HBCR to the BCR showed a maximal rate of missing data of 1.7% (basis of diagnosis) and a maximal rate of conflicting data of 2.8% (basis of diagnosis combined with specific histology). Cooperation between the HBCR and the BCR gives an added value to both registries. The HBCR could be complemented with data from the BCR. The feedback report can increase the completeness and accuracy of the data of the HBCR because it provides a focus on the quality of the data.
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Introduction

In 2003 a Royal Decree defining the criteria for recognition of oncology care programmes was launched.[1] The purpose of these care programmes is to ensure and enhance the quality of cancer care in Belgian hospitals to all patients for whom a multidisciplinary report of treatment decision must be available. One of the criteria is the realisation of a systematic registration of all cancer cases diagnosed and/or treated in the hospital. Therefore, a standardised registration form was introduced in the Belgian hospitals. This form, which was made available digitally in our centre, comprises a minimal data set of patient administrative data, tumour-related data, treatment data and follow-up data (*Table 1*).[2,3] Since this Royal Decree, cancer registry data in Belgium are collected primarily on two levels: in hospital-based cancer registries (HBCR) and in a central

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Table 1. Minimal cancer registration data set	
Administrative data	date of birth
	gender
	ZIP code
Diagnostic data	incidence data (according to international classification)
	basis of diagnosis
	WHO-performance status at diagnosis
Clinical data	grade of differentiation *
	tumour localisation *
	lateralisation
	pathohistological diagnosis *
	clinical TNM stage **
	pathological TNM stage **
	other staging systems
Treatment data	date of first treatment
	executed and planned treatment
Follow-up data	date of first relapse
	disease-free interval
	basis of diagnosis of relapse
	extent of relapse

* *According to International Classification of Diseases for Oncology (ICD-O-3), 3rd edition*
** *TNM Classification of malignant tumours, 7th Edition*

national Belgian Cancer Registry (BCR). These registry settings have similar methods of operation, but different goals. The primary goal of the BCR is to determine cancer incidence rates and trends in order to guide cancer control and prevention strategies at a regional or national level.[4] As such, it provides data for conducting epidemiological studies and allows for studies of the efficacy of treatment, such as patterns of care or quality of care. On the other hand, HBCRs are a means to monitor and evaluate the activity, quality and outcome of cancer care at hospital level. At the same time, they provide a data source for conducting clinical trials.

For the collection of data the BCR depends mainly on the data delivered from HBCRs and pathologists (*Figure 1*). Since 2003, hospitals must report the cancer registry data to the BCR within six months after the end of the year during which the registration took place.[1] There is also an obligation to provide the BCR annually with each pathological and/or biological test corresponding to a diagnosis of cancer.[5] The BCR is legally responsible for the collection, quality control, processing and analysis of the data. The BCR-data are completed with claims data from the Health Insurance Companies. These data mainly include for every patient the information on diagnostic and therapeutic procedures. Follow-up data on vital status and/or date of death are continuously retrieved from the National Registry which retrieves these data from the Crossroads Bank for Social Security.

The cancer cases collected by the HBCR are mainly extracted from the listings of the multidisciplinary discussions and pathology reports (*Figure 2*). Every pathology report which describes a malignancy is forwarded to the data managers. The listings of the multidisciplinary discussions are based on notifications by the treating physicians of the different specialties.

The collaboration between the BCR and the HBCR of the Comprehensive Cancer Centre of the Universitair Ziekenhuis Brussel (CCC-UZB) was started in 2003. Since then, the HBCR of the CCC-UZB is carried out by means of an in-house made software application. Annually, a data file is sent to the BCR. To analyse the effectiveness and optimise the data accuracy of both cancer registries (HBCR and BCR) a collaboration was set up in two ways between the BCR and the HBCR of the CCC-UZB. First the CCC-UZB asked a feedback report from the BCR about the completeness of the data delivered by the HBCR for the year 2005 and the quality of the data delivered by the HBCR for the year 2006.

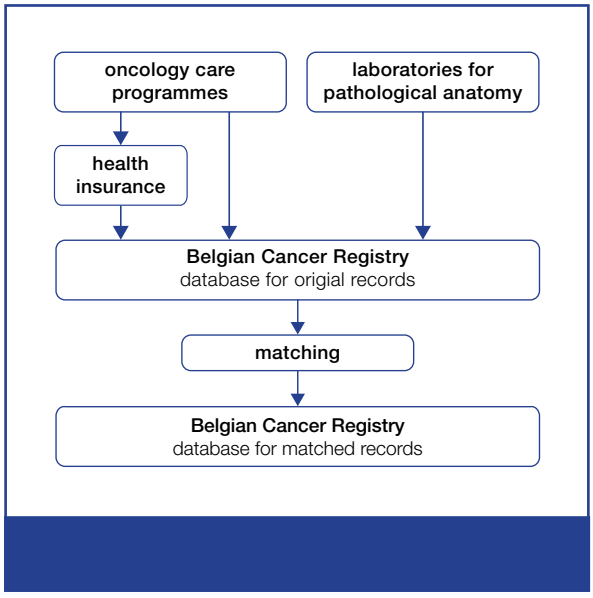

Figure 1. Ways of case recording by the BCR

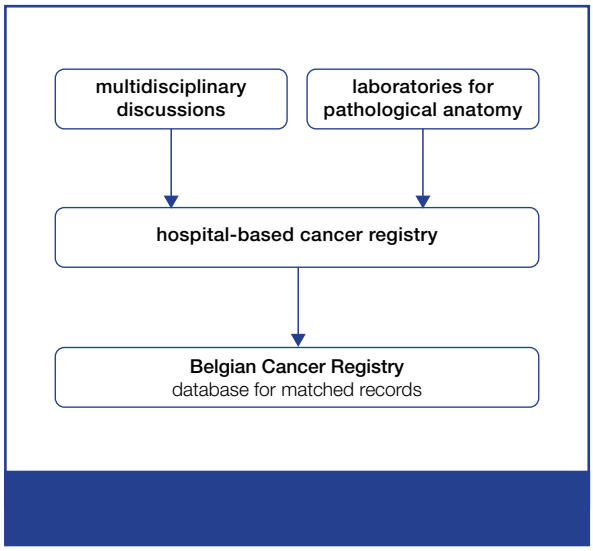

Figure 2. Ways of case recording by the HBCR

Secondly, a pilot study on newly diagnosed head and neck cancer patients for the year 2005 and 2006 was executed in order to exchange clinical data between the HBCR to the BCR and vice versa. The goal of the pilot study was the completion of both databases and to analyse the direction in which the data were exchanged. The data examined are the dates of death of the newly diagnosed head and neck cancers in 2005 and 2006. We looked for dates of death available in the BCR database which were not available in the HBCR database and vice versa. Furthermore, we evaluated if it is appropriate to extend the data exchange to all tumour sites and more follow-up data for future analysis allowing to compare the outcome of cancer care in the CCC-UZB in a more accurate way. We want to put in evidence the shortcomings of both HBCR and BCR and for the future to improve the accuracy and completeness of the data.

Materials and methods

The tumours which have to be registered are listed in *Table 2*.[6] All invasive or in situ cancers with an incidence date in 2005 or 2006 and diagnosed and/or treated and followed after treatment in the CCC-UZB were included in the pilot study. Benign or borderline tumours classified according to the rules of the International Classification of Diseases for Oncology 3rd Edition (ICD-O-3), are not included in the pilot study.[2] Patients who were diagnosed but not treated at the CCC-UZB were not included, and neither were patients who were referred to the CCC-UZB for (a part of) their treatment (e.g. radiotherapy). The follow-up data that are available at the HBCR are the date of death and data about the first relapse (date, basis of diagnosis and the extent of the relapse). In the BCR, only the date of death is collected systematically for all HBCRs patients in Belgium. These data are continuously retrieved on an automated basis from the National Registry (Population Registry). Therefore the BCR has more dates of death available, in particular from patients who are lost to follow-up in the hospital where they were treated and/or diagnosed.

The data source in the HBCR is the electronic medical file of the patient. In this file all data necessary for the registration of the minimal data set are available (e.g. pathology report, reports about diagnostic examinations and treatments such as surgery).

Other follow-up data such as side-effects, disease or progression-free survival are not systematically registered in the HBCR and the NCR.

Results

Pilot study on newly diagnosed head and neck cancer patients

A total of 95 head and neck cancer patients of the CCC-UZB were registered in the BCR for the years 2005 and 2006. Up to 2011, 55 patients were deceased according to the BCR database. In the HBCR database 32 dates of death were available (58%) so that it could be supplemented with the information of 23 dates of death (42%) by the BCR.

Table 2. List of tumours required to be registered (defined by Royal Decree[1])

All invasive malignant tumours
All in situ malignant tumours
All haematological tumours including myeloproliferative diseases and myelodysplastic syndromes
All tumours of the central nerve system including benign tumours and tumours of low malignant potential.
All transitional cell tumours including tumours with low malignant potential
All malignant and borderline epithelial tumours of the ovary
Excluded
Basocellular carcinoma
Haemangioma of the central nerve system

The HBCR database did not contain any supplementary information on cancer deaths when compared to the BCR database.

Feedback report from the BCR (data delivered to the BCR for the year 2005 and 2006)

Completeness of registration (data of the year 2005)
In 2005, the CCC-UZB (regardless of delivery method) recorded 1,305 new malignant diagnoses. Seventy-seven percent of the total number of diagnoses was provided by the HBCR. In the registration of 2005, 299 (23%) new diagnoses were provided by the pathology department and not by the HBCR of the CCC-UZB. Further analysis of a sample of 50 of these cases showed that all of these cases were referred for histopathological analysis only from other hospitals. In these cases, the patients did not undergo any examination (other than the pathological analyses) or treatment in our hospital. Accordingly, a registration through the HBCR could not be carried out properly. We can state that there is no important underregistration in the HBCR and that the completeness of registration is near 100%. Furthermore, the pathology department of the CCC-UZB is important for the referral of specimens for histopathological analysis.

Quality of supplied records (data of the year 2006)
In 2006, a total of 1,250 records was retained by the BCR. Validation of the data showed a very high quality of the clinical records at CCC-UZB. Additional information was requested at the UZB for only sixteen records (1.3%). The specificity for tumour localisation and histology of the record is even optimal (100%). The main points are missing variables and some conflicting data in the registration. The basis of diagnosis is the most common missing value (1.7%). Registering technical/clinical diagnosis as the basis of diagnosis combined with a histological diagnosis is the most frequently occurring conflicting data (2.8%) (*Table 3*). In general, the delivery of TNM-data was good except for malignant melanoma (61.5% missing TNM-data).
Only 3% of the cases were diagnosed purely on clinical and/or technical basis. The percentage of microscopic verification in the Scandinavian countries, The Netherlands, France and Austria is somewhere between 89% and 98%.[7] A small underregistration of diagnoses in an advanced stage, a palliative setting or in elderly patients (tumours of bile ducts, pancreas, lungs, brains) is possible and cannot be excluded.

Table 3. Quality of supplied records (=1,250): missing variables and conflicting data

Missing variables	Number missing (%)
Histology	15 records (1.2%)
Tumour localisation	8 records (0.64%)
Basis of diagnosis	22 records (1.7%)
Conflicting data	
Date of first treatment before incidence date	6 records (0.5%)
Technical/clinical basis of diagnosis combined with specific histology	36 records (2.8%)
Basis of diagnosis by histology combined with unknown topography	6 records (0.5%)

Discussion

The validity and completeness of cancer registration data delivered by the HBCR are two important issues for the BCR because the BCR reports on cancer incidence and survival. Data are also used to underpin decision making and serve for different national and international (comparative) studies.[8-14]
Cancer care involves the continuum of prevention, diagnosis, treatment and follow-up. The systematic registration of a minimal data set for the diagnosis and initial treatment of all newly diagnosed cancer patients became mandatory in 2003. On the other hand, there is no systematic registration in the BCR or the HBCR of follow-up data like the relapses or progressive diseases and the consequent treatments, side-effects of treatment and cause of death. Nevertheless, these data are essential to evaluate the quality of cancer care in or between hospitals.
CCCs and university hospitals treat a lot of patients that are referred for particular treatments. Once the treatment is given the patients are going back to the referring hospital for further follow-up. For these patients even less follow-up data are available in the HBCR.

A major disadvantage is that these data are not systematically recorded but only if preceded by an officially registered multidisciplinary consultation (obligatory for reimbursement of the act). Since 2003, the multi-

disciplinary consultation is honoured separately in Belgium. For every new diagnosis of cancer or follow-up issue (e.g. a recurrence) which is discussed in a formal multidisciplinary consultation, a fee is provided and includes the payment for the registration of the minimal data set. However, if a new cancer diagnosis was not subject of an official formal consultation there was still an obligation to send the registration of minimal data set to the BCR. Although this requirement also applies to some follow-up data (e.g. side-effects, date of first relapse), the registration of these data is not carried out systematically.

The most cost-effective solution is probably to establish an automated data transfer from the electronic medical file to the HBCR. Another, more expensive way is to have more designated and well-trained data managers available. However, no or insufficient funding is allocated for automatic data transfer programming or more designated data managers. Until now, the Belgian government has provided funding for data managers through the National Cancer Plan. However, although this funding is supposed to be sufficient to register the minimal data, it is not sufficient for funding the registration of other follow-up data such as complications, recurrences, progressive disease, causes of death etcetera. A major step would be making the registration of these data just as mandatory as for the minimal data set.
The feedback report revealed that there is a possible underregistration in an advanced stage, a palliative setting or in elderly patients. Underreporting of cancer cases is also an issue in other cancer databases such as the SEER (Surveillance Epidemiology and End Results). The SEER collects data on cancer cases from various locations and sources throughout the United States (US). It currently covers approximately 28% of the US population compared to 97% coverage of the BCR.[15] In the SEER a policy change of the Department of Veterans Affairs (VA) regarding sharing of VA cancer data resulted in incomplete reporting of VA hospital cases in some central cancer registries. Underreporting appeared to be more extensive for some population subgroups (e.g. adult black males and males age 50+) and cancer sites (e.g. pancreas and liver and intrahepatic bile duct).[16] Although the feedback report showed that the underregistration is limited, further analyses of possible underregistration seem interesting to optimise completeness and finding triggers to trace all cancer diagnoses in the hospital.

Accuracy of patient and tumour characteristics and disease severity is important in assessing risks, which is an important issue in outcome research. Because these data are not available in other databases (e.g. minimal clinical data) other existing registries can be used to retrieve these data. In the report of the Belgian Healthcare Knowledge Centre regarding the volume of surgical interventions on its impact on outcome it was shown that many hospitals - low-volume as well as high-volume-missed data on stage of the cancer and that the percentage of missing data varied among these hospitals. On average, 30% of data on stage was missing. For the following cancers, for example, the BCR data have only limited information on the stage: liver and intrahepatic bile ducts (44% of records with a known stage); ovary (54%) and larynx (53%).[8] Although the quality of the clinical records of the CCC-UZB is almost optimal according to the feedback report of the BCR, it is important that continued efforts should be made on creating a record as complete and accurate as possible.
The BCR has a database that contains more data than

Key messages for clinical practice

- Sharing data between national and hospital-based cancer registries can give an added value to both registries.
- Achieving accuracy and completeness of data is of the utmost importance to the Belgian Cancer Registry and should therefore be a major concern for hospital-based cancer registries.
- Cooperation between the hospital-based cancer registries and the Belgian Cancer Registry can enhance data quality.

the HBCRs because of the linkage with population registries and the insurance companies. Therefore collaboration between the BCR and the HBCR in exchanging follow-up data could complement the database of the HBCR and provides the CCC-UZB necessary data for conducting outcome research. However, important data like the cause of death and whether death is disease-related, is still missing.
Considerable time and staff can be saved by exchanging follow-up data in a systematic way. Currently there are approximately 0.3 full-time equivalents (fte) appointed in the HBCR to contact general practitioners and insurance companies in order to obtain data about the date of last contact and, in case of death, to retrieve the date of death.
In Belgium, the recording of data in the HBCR is carried out by data managers that are not employed by the BCR but by the hospitals. This has the advantage that data are more accessible but has the disadvantage that the quality and uniformity of the data are lower. However, this can be overcome by the use of adequately and highly-trained personnel as in the HBCR of the CCC-UZB. By deploying such personnel, the number of missing values and conflicting data is limited to a minimum.

The BCR has the responsibility for the final data quality and completeness of their database but therefore needs the power, authority and means to intervene when the quality and/or completeness of HBCR data are not meeting the required standards and quality.

Conclusion

The importance of complete and accurate cancer information is indisputable. Cooperation as proposed in this study gives an added value to both the BCR and the HBCR. It allows the HBCR to identify shortcomings and make adjustments to build a more accurate complete database which is passed on to the BCR. Moreover, the HBCR complements its database with follow-up data such as the vital status and/or the date of death.
It would be an added value to the BCR and the HBCR if more follow-up data were recorded. However, in spite of the fact that the registration of some follow-up data is mandatory, they are not routinely registered by the HBCR's. In order to fulfil this task more funding is essential.
Collaboration between both levels of cancer registration provides a focus on the quality completeness of registration on which studies and decisions are based.

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