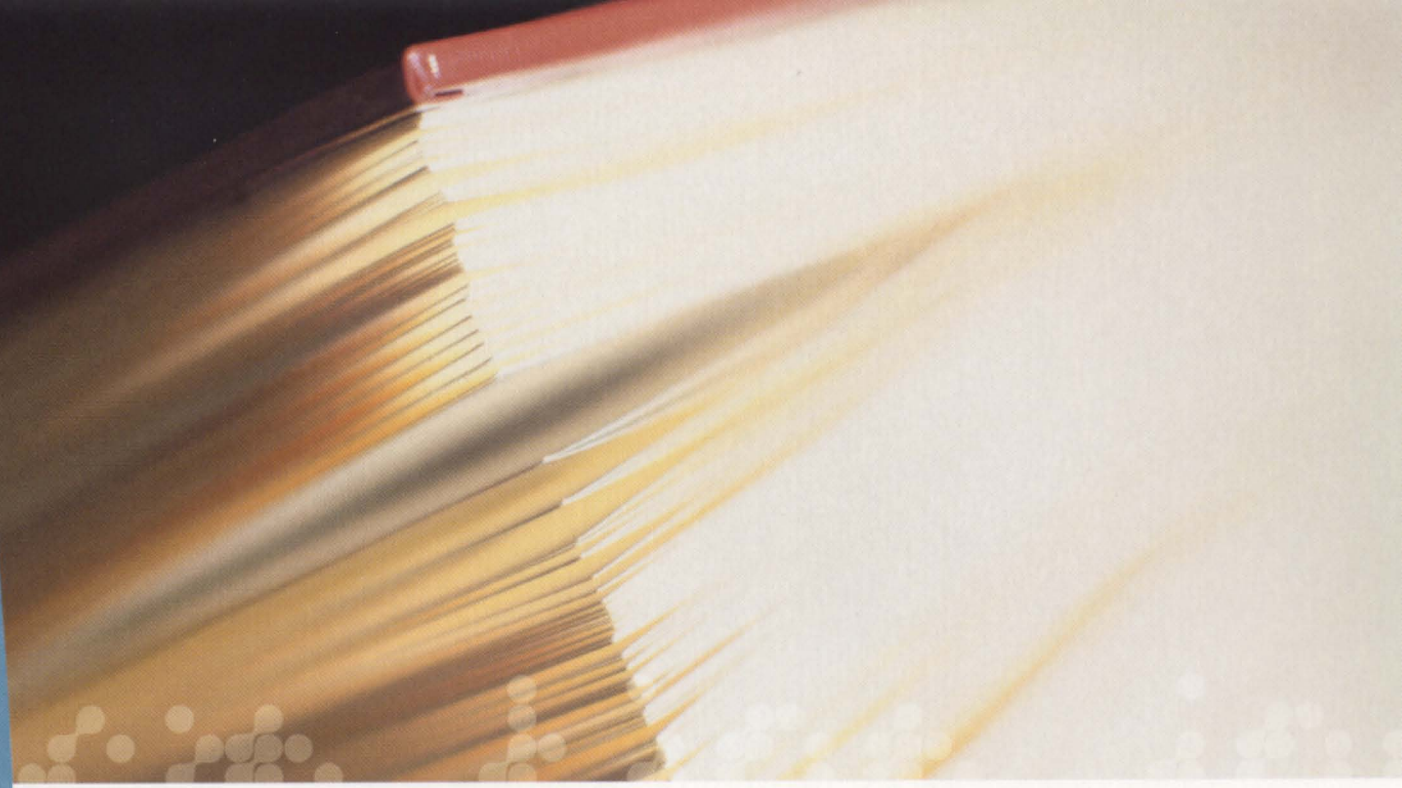

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EVALUATION OF THE COMPLETENESS OF THE *FICHIER DES TUMEURS DU QUÉBEC*

INSTITUT NATIONAL DE SANTÉ PUBLIQUE DU QUÉBEC

Québec

EVALUATION OF THE COMPLETENESS OF THE *FICHIER DES TUMEURS DU QUÉBEC*

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Institut national de santé publique Québec

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SUMMARY

There are four components to the quality of a cancer registry: completeness, validity of data, timeliness of access to data, and range of information available. Evaluating the completeness of the registration of new cancer cases is therefore a priority activity for any cancer registry. Evaluation of completeness is especially important for the *Fichier des tumeurs du Québec* which, unlike its counterparts in Canada's other provinces, uses essentially a single source of data, the MedÉcho file. This file includes data for all day surgeries and hospitalisations in acute care hospitals in Quebec. The purpose of this study is to estimate the completeness of the *Fichier des tumeurs du Québec* with respect to the registration of new cancer cases confirmed by histology in1996.

The method used to estimate completeness is known as "case-refinding." It consists in identifying a series of new cases by reviewing pathology reports and then verifying whether these cases are registered in the *Fichier des tumeurs du Québec*. Completeness is measured by the percentage of new cases entered in the *Fichier des tumeurs du Québec*.

Eligible for inclusion were all new invasive cancer cases for all sites (ICD-9 140-208, except for skin cancer other than melanoma, ICD-9 173) diagnosed in 1996 among all Quebec residents. The new cancer cases evaluated are those confirmed on a tissue sample examined in a pathology laboratory among individuals aged 20 and over (adult). Among individuals under 20 years of age (children and teens), the study was extended to all cancers, whether or not they were confirmed by histology.

Among adults (≥ 20 years of age at time of diagnosis), 963 new cases of cancer were identified by reviewing hospital pathology reports for the periods sampled. Of those cases, 886 were registered in the *Fichier des tumeurs du Québec*, resulting in a crude completeness of 92.0% (95% CI: 90.3%-93.7%). Completeness for melanoma and prostate cancer cases was lower, at 65.4% and 67.9% respectively. For other cancer sites, completeness reached 95.9%.

Among youths (< 20 years of age at time of diagnosis), out of a total of 210 cases counted, 203 were in the *Fichier des tumeurs du Québec*, for a completeness of 96.7% (95% CI: 94.2%-99.1%).

Twenty-five percent of the adult cases that were not included in the *Fichier des tumeurs du Québec* (19/77) involved day surgery or hospitalization. For younger persons, the percentage was 71.4% (5/7).

Although the *Fichier des tumeurs du Québec* receives its data from a single source (the MedÉcho file), its completeness is high; for adults, it reaches more than 95% for most cancers confirmed by histology. On the other hand, completeness is lower for some types of cancer, such as prostate cancer and melanoma. This reduction in completeness is mainly attributable to two factors: first, some cancers, such as prostate cancer and melanoma, can be diagnosed and treated without any hospitalization or day surgery. Since they do not appear in MedÉcho, these cases cannot be identified by the *Fichier des tumeurs* under the

current system. Second, some cancer cases are not included in the *Fichier des tumeurs du Québec* even though they involved day surgery or hospitalization. These cases should be registered in the *Fichier des tumeurs du Québec* under the current system.

The completeness of the *Fichier des tumeurs du Québec* could be improved by optimizing the current system for identifying cases using MedÉcho. Completeness could also be improved by adding other data sources. Radiotherapy centres, the file on for-fee services covered by the Régie de l'assurance-maladie du Québec as well as pathology and hematology laboratories are all sources to consider for completing the identification of new cancer cases in Quebec that do not involve any day surgery or hospitalization.

It would be advantageous for the *Fichier des tumeurs du Québec* to evaluate its performance and strive to achieve a level of quality that would enable it to be certified by the North American Association of Central Cancer Registries (NAACCR), not only for completeness but for all the criteria that must be met in order to obtain this certification.

The *Fichier des tumeurs du Québec* shows very good completeness for new cancer cases confirmed by histology for adults and excellent completeness for youths.

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INTRODUCTION

Cancer registries are essential tools for monitoring cancer.[1,2] There are four main components to the quality of this type of registry: completeness, validity of data, timeliness of access to data, and range of data available.[3]

Completeness refers to the ability of a cancer registry to identify and register all new cancer cases diagnosed within a population. Completeness can vary considerably from one place to another, because of variations in resources and data collection methods, or variations in diagnostic examinations. An excellent level of completeness is essential in order to produce accurate statistics and conduct valid studies on cancer in a population. Evaluating the completeness of registration of new cases is therefore a priority activity for all cancer registries.

The completeness of the cancer registry is an especially important concern for Quebec. In Canada's other provinces, several sources are used to supply data to the cancer registries, foremost of which are pathology reports. A single data source is used to supply data to the *Fichier des tumeurs du Québec*, namely the MedÉcho file, which contains basic information on all day care surgeries and all hospitalizations in acute care hospitals in Quebec. Because the *Fichier des tumeurs du Québec* does not use pathology reports, it is possible that some cancers confirmed by histology, which account for the vast majority of cancer cases, might not be identified and entered in the registry if the diagnosis and treatment are done entirely without hospitalization or day surgery.

Statistics Canada has decided to set up and fund a project to evaluate the completeness of cancer case reporting in Canada. This project is being carried out in co-operation with four provincial cancer registries, namely those of Alberta, Manitoba, Ontario and Quebec.

Considering the importance of the *Fichier des tumeurs du Québec* and questions concerning its completeness, the Institut national de santé publique du Québec (INSPQ) felt it essential to participate in this project and quantify the completeness of the *Fichier des tumeurs du Québec*. Since the main concern regarding the Quebec registry has to do with the completeness of the registration of new cancer cases confirmed by histology, the INSPQ has focused more specifically on evaluating the completeness of the registration of this type of case.

OBJECTIVES

The purpose of this study is to estimate the completeness of the registration of new cancer cases confirmed by histology for the year 1996. For cancer in children and teens, the study was extended to cancers confirmed by methods other than histology (mainly by hematology) because of the rarity of cases in that part of the population.

Another purpose of the study is to describe this completeness by cancer site and the age and sex of the patient.

1 METHODS

1.1 POPULATION

The method used to estimate completeness is known as “case-refinding.” According to this method, a series of new cancer cases is identified by reviewing pathology reports. Among these new cases, those registered in the *Fichier des tumeurs du Québec* are identified through linking. Completeness is measured by the proportion of new cases found in the *Fichier des tumeurs du Québec*.

The study concerns new cancer cases, whether adult (≥ 20 years of age) or pediatric (< 20 years of age) diagnosed in 1996 among Quebec residents. When collection of the data began, the *Fichier des tumeurs du Québec* was complete up to 1998. The choice of the year 1996 therefore allows a two-year time period for cases to be registered in the *Fichier des tumeurs du Québec* following the diagnosis of cancer.

For adults, new cancer cases evaluated are those confirmed by a tissue sample examined in a pathology laboratory. For pediatric cases, new cases are those confirmed by all sources (histology, hematology and others).

The study concerns only invasive tumours, and it covers all sites (ICD-9 140-208) except for skin cancer other than melanoma (ICD-9173).

1.2 SAMPLING PLAN

Assuming that the completeness of the *Fichier des tumeurs du Québec* lies between 85% and 95%, a sample of 1,200 cases is needed in order to obtain the desired accuracy, i.e., a 95% confidence interval with a range not exceeding 4% (Cochran, 1967).

1.2.1 Adult Cases (≥ 20 years of age)

For adults, data collection calls for creating a random sample representative of new cases while minimizing the number of institutions to be visited.

Essentially, we had a database containing the list of institutions in which cancer cases were diagnosed for 1996, as well as the number of cancer cases reported in each institution for the same year. Those institutions that diagnosed fewer than 10 cancer cases and hospitals that had closed since 1996 were excluded from the study. Institutions were then divided into five strata according to the number of cases reported to the *Fichier des tumeurs du Québec* in 1996.

Table 1 describes the approach used to construct the sample of new cases studied. In the table, institutions are grouped into five strata according to the number of new cases reported to the *Fichier des tumeurs du Québec* in 1996. For each group (stratum) of hospitals, the

table first gives the total number of new cancer cases reported to the *Fichier des tumeurs du Québec* for 1996. For example, the first group (the first stratum) includes 12 institutions that reported the greatest number of cases in 1996 (≥ 800 cases). Collectively, these hospitals saw 12,669 new cancer cases, representing approximately 40% of the 31,133 new cases registered in the *Fichier des tumeurs du Québec* that year. Table 1 also gives the number of cases required in each stratum. This number was set in advance when the sample size was calculated. With this information, the average number of cases diagnosed monthly in each hospital could be estimated. Then the number of institutions to be sampled in each stratum was determined, taking account of the number of cases required and the monthly number of cases diagnosed per institution. In order to keep the number of institutions to be visited as low as possible, the time period (in months) to be covered could vary from 1 to 4 months, depending on the stratum. When this strategy is applied, the distribution of cases obtained in the sampling is similar to the distribution of cases reported in Quebec in 1996.

1.2.2 Pediatric Cases (< 20 years of age)

A sixth stratum was added for the three main institutions treating pediatric cancer cases in Quebec (Table 1). No sampling plan was developed for this stratum because of the rarity of cancer in children and teens. All cases under 20 years of age reported in 1996 by these hospitals were included in the study.

Pediatric cancer cases (< 20 years of age) identified in the review of pathology reports from general hospitals mainly treating adult cases were included in the estimate of completeness for that age group.

For the Centre Hospitalier de l'Université Laval, which has a pediatric unit specializing in cancerology in addition to being a general hospital, cases were divided into two groups according to the age of the patients at the time of diagnosis (< 20 and ≥ 20). Pediatric cases were included in stratum six. Cases aged 20 and over were included in the analysis of completeness for adults.

1.3 DATA COLLECTION

Once authorizations were obtained from the Commission d'accès à l'information du Québec (CAIQ) and the directors of professional services at the institutions concerned, two certified records technicians, one with certification in oncology (Certificated in Tumour Registry), specially trained for this study, visited the 33 institutions sampled for adult cases, along with the three main pediatric institutions.

For strata 1 to 5, all pathology reports for the months sampled were reviewed in order to identify those with a cancer diagnosis. For stratum 6, all cases of malignant tumours were identified from various sources (primarily the research files of some members of the Pediatric Oncology Group, files of hematology departments and records departments). Thus, for pediatric cases from institutions in stratum 6, efforts were made to identify all cancer cases, even those not confirmed by histology.

Data from cases identified in the review of pathology reports were captured in a database using a portable computer. Registration of these cases in the *Fichier des tumeurs du Québec* in the years 1996 to 1998 was then checked on site by means of linking. This process used the health insurance number, the name at birth, the given name and the cancer site. The software for capturing case data and linking them with data from the *Fichier des tumeurs du Québec* was developed specially for the needs of this study.

For cases not found in the *Fichier des tumeurs du Québec* between 1996 and 1998, a second linkage was done with data from the *Fichier des tumeurs* for the years 1993 to 1995 in order to identify recurrences.

For cases not found in the *Fichier des tumeurs du Québec* either in 1996-1998 or in 1993-1995, the medical record in the institution's records department was reviewed to determine whether the case in question was a new case or a recurrence. This review of the record also served to characterize new cases that had not been registered in the *Fichier des tumeurs du Québec*.

To ensure that the data were kept confidential and secure at all times, the portable computer and the content of the hard disk were made secure by using a GemPlus smart card that made it possible firstly to limit access to the computer and secondly to encrypt the disk. The portable had a numerical identification key guaranteeing confidentiality of communications, integrity of messages and non-repudiation of transactions. The project received the approval of the Commission d'accès à l'information du Québec (CAIQ).

1.4 PROCESSING AND ANALYSIS OF DATA

When data collection was completed, the data were cleaned up. A few cases had been identified more than once. These duplicates were eliminated.

Incident cancer cases identified were classified into three categories: linked, unlinked and possibly linked. Linked cases are those located in the *Fichier des tumeurs du Québec* with a similar health insurance number, name at birth, given name, cancer site and date of cancer diagnosis. "Possibly linked" cases are those located in the *Fichier des tumeurs du Québec* with a similar health insurance number, name at birth, given name and diagnosis date but differences in the morphology or topography of the cancer. Possibly linked cases were reviewed by the project team and assigned a definitive category (linked or unlinked).

For unlinked cases, more research was carried out afterward on the body of data available in the *Fichier des tumeurs du Québec*, and the same rules were followed by the project team to eliminate recurrences and assign a definitive category (linked or unlinked) to the remaining cases.

The statistical formula used to estimate the weighted completeness and the confidence interval, taking our sampling plan into account, is shown in Appendix I This weighted completeness may be compared to crude completeness to measure the statistical effect of the sampling plan.

2 RESULTS

2.1 COMPLETENESS FOR ADULTS (≥ 20 YEARS OF AGE)

Table 2 shows the distribution of 963 cancer cases identified among adults in relation to the cases required and expected by stratum in the sampling plan. The number of cases identified is slightly lower than the number required (1,050) or expected (1,161).

Of the 963 cases, 886 were linked and are therefore to be found in the *Fichier des tumeurs du Québec*, for a crude completeness of 92.0% (95% CI: 90.3%-93.7%) (Table 3). When the effect of the sampling plan is taken into account, the weighted completeness remains at 92.0% and the 95% confidence interval is scarcely any broader (95% CI: 90.2%-93.9%).

Completeness varies slightly from one stratum to another (Table 4). For hospitals that annually report a small number of new cancer cases (stratum 5: 10-41 cases in 1996), completeness is lower. For the other strata, completeness tends to increase when the number of reported cases declines.

Table 5 shows where the 77 tissue samples were taken that proved to be new cases of malignant tumours but were not to be found in the *Fichier des tumeurs du Québec*. As the table indicates, 75.3% of the cases not registered in the *Fichier des tumeurs* had been collected in outpatient clinics or outside the hospital setting and 24.7% of the cases involved day surgery or hospitalization.

These same 77 cases not registered in the *Fichier des tumeurs du Québec* were then distributed according to cancer site and location of the tissue sampling (Table 6). This revealed that 30 of the 34 cases of prostate cancer not registered in the *Fichier des tumeurs* were from outpatient clinics, as were 7 of the 9 cases of melanoma.

Table 7 shows completeness by cancer site. For most sites, completeness is greater than 90%. However, completeness for cases of melanoma and prostate cancer is lower, at 65.4% and 67.9% respectively. For bladder cancer, completeness is 86.0%. According to the data in Table 8, if melanoma and prostate cancer are excluded, overall completeness reaches 95.9%, and each stratum has greater than 90% completeness.

Finally, an analysis of overall completeness by age group and sex (for non-gender-specific cancers only) shows no statistically significant variation (Table 9). Only in melanoma cases does completeness differ by sex: 84.6% for males compared to 46.2% for females (Table 10).

2.2 COMPLETENESS FOR YOUTHS (< 20 YEARS OF AGE)

In the under-20 age group, 210 new cancer cases were identified, including 203 from stratum 6 hospitals (pediatric hospitals) and 7 from hospitals in strata 1-5 (hospitals sampled for the adult part of the study).

Of the total of 210 pediatric cases, 203 were found in the *Fichier des tumeurs du Québec*, for a crude completeness of 96.7% (95% CI: 94.2%-99.1%) (Table 11). Completeness does not vary according to the institution (Table 12). For the 7 cases under 20 years of age identified in strata 1-5 (largely adult general hospitals), all were included in the *Fichier des tumeurs du Québec*.

Table 13 shows the location of tissue sampling for the 7 cases that proved to be new cases of malignant tumours but were not found in the *Fichier des tumeurs du Québec*. As may be seen, in 71.4% of the cases not registered in the *Fichier des tumeurs* (n=5), tissue samples were taken during a hospitalization.

For most cancer sites, completeness is greater than 90% (Table 14). The eye and the endocrine glands are the only two sites that have an apparently lower completeness rate, at 78.8% and 88.9% respectively. However, these estimates are based on a very small number of cases, making them statistically unreliable. Completeness varies little or not at all by age and sex (Table 15).

Completeness appears to vary slightly according to the mode of diagnosis (Table 16). Cases confirmed by histology, representing 80% of cases, have 97.0% completeness. For cases confirmed only by hematology, the completeness is 100%. However, for cases confirmed by other means, the completeness is 82%, although these cases account for only 5% of the cases for this age group.

3 DISCUSSION

This study shows that the *Fichier des tumeurs du Québec* is highly complete for new cases confirmed by histology. For these cases in the 20 and over age group, the overall completeness of the *Fichier des tumeurs du Québec* is 92%. However, the completeness of cases confirmed by histology varies according to the site. In particular, prostate cancer and melanoma have a low completeness (67.9% and 65.4% respectively), while for the other sites combined, which account for some 85% of new cases, completeness is very high at 95.9%. For the under 20 age group, completeness reaches 96.7%, irrespective of whether or not the cancer is confirmed by histology.

The completeness of cancer registries as observed in other studies on cases reported between 1993 and 1996 varies from 89.6% to 97.4%.[2-5] Caution should be exercised when comparing those studies with this one. Those studies concern all new cases, regardless of whether or not they have been confirmed by histology. Also, the data sources used to evaluate completeness (e.g., review of pathology reports, medical records or death certificates) varied from one study to another.

For adults, the goal of the sampling process was to assemble a representative series of new cancer cases diagnosed in 1996. The number of cases identified (n=963) is slightly lower than the number expected according to the sampling plan (n=1,161). The smaller number of cases could be due to the fact that the calculation of the expected number of cases was based on the total cases reported in the *Fichier des tumeurs du Québec*, all methods of diagnostic confirmation combined, whereas only cases confirmed by histology were retained for adults. In 1996, of the new cases for which the mode of diagnosis was known, 82.4% had been confirmed by histology. And the 963 cases identified in adults represent 82.9% of the 1,161 cases expected. The consistency of these figures suggests that the sampling process used in this study worked relatively well.

For children and teens, the series of cases was basically drawn from Quebec's three main pediatric hospitals, on the assumption that almost all pediatric cases were seen in them in the year following diagnosis. In 1996, the *Fichier des tumeurs du Québec* registered 203 new cases of cancer in children under 15 years of age and 94 in those aged 15 to 19. Among those under 15 years of age, we identified 182 cases, which is equivalent to 89.7% of the 203 cases registered in the *Fichier des tumeurs* for this age group in 1996. Therefore, the completeness estimated on the basis of our series of cases applies to the vast majority of new cases under 15 years of age diagnosed in Quebec. For the 15-19 age group, the percentage is lower (29.8%), probably because these cases are more similar to adult cases and are often treated in general hospitals other than pediatric hospitals. While the number of cases under age 15 and 15-19 that are identified in general hospitals is small (n=7), the 100% completeness observed for these few cases is reassuring.

The main criticism levelled against the *Fichier des tumeurs du Québec* with respect to its completeness is that it does not use pathology reports to identify new cancer cases. On this subject, the present study is mainly reassuring. The results show that if pathology reports were added as a source of cases to the *Fichier des tumeurs du Québec*, this would do little

to improve completeness for most cancers, including lung, breast and colon cancer. These findings are reassuring as to the validity of Quebec incidence and survival statistics for these cancer sites. They are also encouraging for researchers who would like to use the *Fichier des tumeurs du Québec* for studies on these cancers. The excellent level of completeness for most cancers confirmed by histology should not be too surprising. For almost all cancers, the period of diagnostic investigation, characterization of the disease and initial treatment is intensive. With the shift to ambulatory care, a large share of the tests and treatments are being carried out in an outpatient setting. However, for the vast majority of cancers, it is still relatively rare to be able to perform all investigations and all initial treatments without at least a brief hospitalization or day surgery.

Nevertheless, our findings show that completeness is lower for prostate cancer and melanoma. The problem of low completeness for melanoma is already well known. The same problem has now been identified with respect to cancer of the prostate, a frequent site of cancer in males. Prostate cancer is seen as a cancer that often develops slowly and can sometimes be treated relatively effectively by hormone therapy or radiotherapy without even completely removing the primary tumour. Our findings cast doubt on the validity of incidence and survival data for prostate cancer and melanoma. Data from the *Fichier des tumeurs du Québec* appear to be of limited use for conducting research on prostate cancer or melanoma or for tracking efforts to combat them.

Our research concerns only cases confirmed by histology. In the *Fichier des tumeurs du Québec*, as in a number of other registries, some 80-85% of cancers are confirmed only by cytology, radiology or clinical examinations (Table 17). In general, cancer registries, including the *Fichier des tumeurs du Québec*, have limitations as to the registration of these cases. For children, completeness reaches 95.1% for this type of case. While encouraging, this result may not reflect the situation with respect to adults. The completeness of the registration of new cancer cases not confirmed by histology should be evaluated.

Some steps could be taken to improve the completeness of the *Fichier des tumeurs du Québec*. First, completeness could be improved without even changing the registry's current method of identifying cases by means of MedÉcho. Our study shows that a relatively large proportion of cases not registered in the *Fichier des tumeurs* (71.4% for those under 20 years of age; 24.7% for those 20 and over) had undergone hospitalization or day surgery. The failure of the current system may have occurred at various points in the process: when physicians entered their diagnosis on hospital forms, when records technicians were preparing data for MedÉcho, when data were being processed by MedÉcho, or in the *Fichier des tumeurs du Québec* itself. Possibly, an examination of the reasons for this failure to register particular cases would lead to improvements to the current system.

Second, the completeness of the *Fichier des tumeurs du Québec* could be improved by establishing a link with pathology laboratories. The expected gains in completeness would have mainly to do with the reporting of prostate cancer and melanoma, which account for only about 15% of cancers confirmed by histology. However, since prostate of cancer is frequent in males, the gain in completeness would be substantial for purposes of tracking efforts to combat cancer in this portion of the population. A number of pathology laboratories

are now being computerized. Once this process is completed, it may be possible to link up the pathology laboratories and the *Fichier des tumeurs* electronically, thereby reducing costs considerably.

Third, the completeness of registration of new cases confirmed by histology as well as those not confirmed by histology could be improved by using new data sources, such as radiotherapy centres, the file on for-fee services covered by the RAMQ and hematology laboratories. The use of these new sources could improve the completeness of registration not only of prostate cancer and melanoma, but also of cancer sites, as in the case of lung cancer and leukemia, which often have no histological confirmation. It would be useful to examine the potential of these links to improve the completeness of the *Fichier des tumeurs du Québec*, as well as the feasibility of establishing these links and the associated costs.

Lastly, according to our findings, completeness is less in institutions reporting the smallest number of cases in 1996 (stratum 5). All institutions in this group have their tissue samples analysed in other institutions that employ pathologists. Possibly this complicates the task of the personnel of these small hospitals. On the other hand, half the institutions in stratum 4 that follow the same procedure are not statistically different from the other institutions in this stratum that have their own pathologists analysing their tissue samples. Indeed, stratum 4 obtained the highest completeness rating. The reasons explaining the low completeness observed with respect to small hospitals should be studied in greater depth and solutions should be applied.

Efforts to improve the *Fichier des tumeurs du Québec* should not focus solely on completeness, especially since this study suggests that the degree of completeness currently obtained is good. Firstly, the *Fichier des tumeurs du Québec* has a time lag problem in the updating of data. With the current system, the *Fichier des tumeurs* should be practically complete with a lag of at most 12 months. At this point, in mid-June 2003, only the 1999 data are available (and hence there is a 29-month lag for cases dating from early in 2000). Secondly, it is also necessary to assess the validity of the data that are now present in the *Fichier des tumeurs du Québec*. In a study that looked at 270 cases to assess the validity of data in the registry for the year 1992, data validity was found to be generally good, but the data on the morphology of cancers, the date of diagnosis and place of residence seemed more limited.[7] A more thorough and more recent study of the validity of the data in the *Fichier des tumeurs du Québec* would help to better target the actions to be taken to improve it. Lastly, the range of data available for each cancer case registered in the *Fichier des tumeurs du Québec* is currently quite limited. This range should be expanded. Priority should go to incorporating data on the stage. The cancer registry of the SEER network in the United States has contained data on the stage for more than 20 years. Most cancer registries in Canada and Europe now have data on the stage or are making major efforts to obtain such data. The stage is a crucial variable for tracking cancer survival rates over time; it is a key indicator for measuring the impact of improvements in treatments, which is an important aspect of the fight against cancer.

The North American Association of Central Cancer Registries (NAACCR), to which the *Fichier des tumeurs du Québec* and the other Canadian cancer registries belong, has certification criteria that cover the basic aspects of the quality of such registries (Appendix II). Completeness is one of these criteria, but it would be desirable for the *Fichier des tumeurs du Québec* to evaluate its performance and strive to achieve a sufficient level of quality, not only for completeness but for all the criteria for certification by the NAACCR, as soon as possible.

4 CONCLUSION

Although the *Fichier des tumeurs du Québec* is not supplied data by pathology laboratories, the overall completeness of the identification of new adult cases confirmed by histology for the year 1996 is 92.0% (95% CI: 90.3%-93.7%). Completeness varies according to the site of the cancer. Completeness for prostate cancers and melanoma is relatively low (67.9% and 65.4%, respectively), whereas completeness for other cancers in adults is 95.9%.

Completeness is 96.7% for persons under 20 years of age, regardless of whether or not the cancer is confirmed by histology.

The completeness of the *Fichier des tumeurs du Québec* could be improved by using data other than those from MedÉcho, such as from the files of radiotherapy centres, the file on for-fee services covered by the RAMQ, and possibly data from pathology and hematology laboratories.

As regards completeness but also the other aspects of quality, the *Fichier des tumeurs du Québec* should evaluate its situation in relation to the various criteria for certification by the North American Association of Central Cancer Registries (NAACCR). It should then take the necessary corrective actions and strive to achieve a performance sufficient to obtain certification as soon as possible.

TABLES

Table 1 Sampling Method and Number of Cases Expected

Stratum	Annual No. of cases	No. of inst*	No. of cases	%	No. of cases required	Average cases/month	No. of inst* sampled	No. of months	No. of cases expected
1	≥ 800	12	12,669	40.7	350	88	4	1	352
2	300-799	25	12,790	41.1	350	43	9	1	384
3	150-299	15	3,209	10.3	175	18	6	2	214
4	42-149	24	2,001	6.4	131	7	6	4	167
5	10-41	18	464	1.5	44	2	7	3	45
Subtotal	≥ 10	94	31,133	100	1,050		32		1,161
Pediatrics		3			200		3	12	200
Total		97			1,250		35		1,361

* inst = institutions

Table 2 Distribution of Adult Cases Identified, Required and Expected

Stratum	Annual number of cases	Hospitals sampled	Cases identified	Cases required	Cases expected
1	≥ 800	4	375	350	352
2	300-799	9	300	350	384
3	150-299	7	146	175	214
4	42-149	6	92	131	167
5	10-41	7	50	44	45
Total	≥ 10	33	963	1,050	1,161

Table 3 Crude and Weighted Completeness, Adults

Unlinked cases	77
Linked cases	886
Total	963

Crude completeness: 92.0% [95% CI: 90.3-93.7]
Weighted completeness: 92.0% [95% CI: 90.2-93.9]

Table 4 Completeness by Stratum of Institution, Adults

Stratum	Annual number of cases	n	Completeness (%)
1	≥ 800	375	90.9
2	300-799	300	91.7
3	150-299	146	95.9
4	42-149	92	96.7
5	10-41	50	82.0
Total	≥ 10	963	92.0

Table 5 Distribution of Unlinked Adult Cases by Location of Tissue Sampling

Location of sampling	n	%
Outpatient clinic	54	70.1
Day surgery	7	9.1
Hospitalization	12	15.6
Not in institution	4	5.2
Total	77	100.0

Table 6 Distribution of Unlinked Adult Cases by Cancer Site and Location of Tissue Sampling

	Location of sampling				
Site	Outpatient clinic	Day surgery	Hospitalization	Not in institution	Total
Lung	2	0	1	0	3
Breast	1	0	1	0	2
Prostate	30	2	1	1	34
Colorectal	2	0	3	0	5
Lymphoma	3	2	0	1	6
Bladder	3	2	1	0	6
Melanoma	7	1	0	1	9
Oral	1	0	0	0	1
Other	5	0	5	1	11

Table 7 Completeness by Cancer Site, Adults

Cancer site	n	Completeness (%)
Lung	103	97.1
Breast	160	98.8
Prostate	106	67.9
Colorectal	173	97.1
Lymphoma	64	90.6
Bladder	43	86.0
Kidney	15	93.3
Melanoma	26	65.4
Leukemia	9	100.0
Uterus	46	100.0
Pancreas	8	100.0
Oral	31	96.8
Stomach	34	94.1
Cervix	16	100.0
Other	129	93.8

Table 8 Completeness for Prostate Cancer and Melanoma and for Other Cancers, Adults

	Prostate cancer and melanoma		Other cancers	
Stratum	**n**	**Completeness (%)**	**n**	**Completeness (%)**
1	60	68.3	315	95.2
2	39	69.2	261	95.0
3	14	71.4	132	98.5
4	10	80.0	82	98.8
5	9	33.3	41	92.7
Total	132	67.4	831	95.9

Table 9 Completeness by Age Group and Sex, Adults

		n	Completeness (%)
Age	20-49	157	92.4
	50-59	174	94.8
	60-69	286	90.9
	70-79	257	93.0
	≥ 80	89	86.5
Sex*	Male	391	93.9
	Female	222	92.3

* Non-gender-specific cancers only

Table 10 Completeness by Cancer Site and by Sex, Adults

	Males		Females	
Site	n	Completeness (%)	n	Completeness (%)
Lung	70	95.7	33	100.0
Breast	-	-	160	98.8
Prostate	106	67.9	-	-
Colorectal	100	95.0	73	100.0
Lymphoma	38	94.7	26	84.6
Bladder	32	87.5	11	81.8
Kidney	9	100.0	6	83.3
Melanoma	13	84.6	13	46.2
Leukemia	6	100.0	3	100.0
Uterus	-	-	46	100.0
Pancreas	5	100.0	3	100.0
Oral	20	95.0	11	100.0
Stomach	27	92.6	7	100.0
Other	76	93.4	69	95.7

Table 11 Completeness, Children and Teens

Unlinked cases	7
Linked cases	203
Total	210

Completeness: 96.7% [95% CI: 94.2-99.1]

Table 12 Completeness by Hospital Centre, Children and Teens

Hospital centre*	n	Completeness (%)
A	117	96.6
B	43	95.4
C	43	97.7
Other	7	100.0
Total	210	96.7

* Hospital centres A, B and C are pediatric hospitals (stratum 6); the "Other" category consists of hospitals in strata 1-5 in which cases under age 20 were identified.

Table 13 Distribution of Unlinked Cases by Location of Tissue Sampling, Children and Teens

Location of sampling	n	%
Hospitalization	5	71.4
Not in institution	2	28.6
Total	7	100.0

Table 14 Completeness by Cancer Site, Children and Teens

Cancer site	n	Completeness (%)
Leukemia	65	100.0
Brain	38	94.7
Lymphoma	29	100.0
Bone and connective tissue	27	96.3
Eye	14	78.6
Urinary tract	7	100.0
Digestive tract	6	100.0
Respiratory tract	5	100.0
Genitals	6	100.0
Endocrine glands	9	88.9
Other	4	100.0
Total	210	95.7

Table 15 Completeness by Age Group and Sex, Children and Teens

		n	Completeness (%)
Age			
	< 1	19	94.7
	1 to 4	65	96.9
	5 to 9	48	95.8
	10 to 14	50	96.0
	15 to 19	28	100.0
Sex*			
	Male	116	97.4
	Female	88	95.5

* Non-gender-specific cancers only

Table 16 Completeness by Method of Diagnosis, Children and Teens

Method of diagnosis	n	Completeness (%)
Histopathology	169	97.0
Hematology	30	100.0
Not specified	11	81.8

Table 17 Percentage of Histological Confirmation for Selected North American Cancer Registries and Selected Cancer Sites, 1991-1995

	Lung	Breast	Prostate	Colorectal	Melanoma	NHL
Alberta	87.9	98.2	95.0	95.1	100.0	97.4
Manitoba	75.9	94.3	95.0	90.7	99.4	91.5
Ontario	74.2	94.6	90.8	88.1	95.5	86.8
Quebec*	77.2	96.7	91.5	92.7	95.9	90.0
Connecticut	91.5	98.1	97.1	97.2	99.6	97.1
San Francisco	90.2	98.6	96.4	96.8	99.6	95.3

* Excluding cases where method of diagnosis not specified.

APPENDIX I

Effect of Sampling Plan

Notation:

N_h= # of hospitals in stratum h
n_h= # of hospitals selected in stratum h
M_{hi}= total # of records available in hospital (h,i), the i^{th} of stratum h
m_{hi}= # of records examined in hospital (h,i)
y_{hi}= # of tumours not reported in the m_{hi} records examined in hospital (h,i)
$p_{hi}=y_{hi}/m_{hi}$= fraction of tumours not reported for hospital (h,i)

Note: In the formulas below, the sums cover the 5 strata in the study (h goes from 1 to 5) and, in each stratum, the n_h hospitals sampled (i goes from 1 to n_h).

1- Formulas for naive estimation not taking sampling plan into account

Rate of non-reporting $\hat{p}_n = \dfrac{\sum_{h,i} y_{hi}}{\sum_{h,i} m_{hi}}$; Estimate of variance $v(\hat{p}_n) = \dfrac{\hat{p}_n(1-\hat{p}_n)}{\sum_{h,i} m_{hi}}$

2- Formulas conforming to sampling plan

(Sampling stratified to two degrees; see Cochran, p. 305, Equation 11.30)

Rate of non-reporting $\hat{p}_d = \dfrac{\sum_h N_h \sum_i p_{hi} M_{hi} / n_h}{\sum_h N_h \sum_i M_{hi} / n_h}$

and its variance,

$$v(\hat{p}_d) = \frac{1}{\left(\sum_h N_h \sum_i M_{hi} / n_h\right)^2} \sum_h N_h^2 \left\{ \frac{(1-f_h)}{n_h} \sum_i \frac{(z_{hi} - \bar{z}_h)^2}{n_h - 1} + f_h \sum_i \frac{M_{hi}^2 (1-f_{hi})}{n_h^2} \frac{p_{hi}(1-p_{hi})}{m_{hi}} \right\}$$

where $z_{hi}=M_{hi}(p_{hi}- \hat{p}_d)$;
$f_h=n_h/N_h$ is the sampling fraction in stratum h ;
$f_{hi}=m_{hi}/M_{hi}$ is the sampling fraction in hospital (h,i).

APPENDIX II

Criteria and Standards for Obtaining Certification by the North American Association of Central Cancer Registries (NAACCR)

Criteria and Standards for NAACCR Certification *Criteria Evaluated for Each Diagnosis Year*		
Criterion	**Certificate Standard**	***Error Tolerance***
1. Completeness	>=90% Silver	*-1.0*
	>=95% Gold	*-1.0*
2. Passing EDITS	>=97% Silver	*-0.4*
	100% Gold	*0*
3. DCOs	<=5% Silver	*0.4*
	<=3% Gold	*0.4*
4. Timeliness	within 23 months: Silver	
	within 23 months: Gold	
5. Duplicate Reports	<=2/1,000 Silver	*0.4*
	<=1,000 Gold	*0.4*
6. Missing Data Fields -		
Sex, Age, County	<=3% Silver	*0.4*
	<=2% Gold	*0.4*
Race	<=5% Silver	*0.4*
	<=3% Gold	*0.4*

source: http://www.naaccr.org/

* NAACCR: North American Association of Central Cancer Registries

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