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# CANCER SURVIVAL OF NEWLY DIAGNOSED CASES, QUEBEC, 1992

INSTITUT NATIONAL DE SANTÉ PUBLIQUE DU QUÉBEC

Québec

# CANCER SURVIVAL OF NEWLY DIAGNOSED CASES, QUEBEC, 1992

Data Quality Five-year Relative Survival Rates

DIRECTION DU DÉVELOPPEMENT ET DES PROGRAMMES UNITÉ CONNAISSANCE-SURVEILLANCE

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#### 1. INTRODUCTION

Cancer surveillance is one of the Quebec government's leading health concerns because of the growing incidence of the disease in our society. In 1975, diseases of the circulatory system accounted for 47 % of all deaths in Quebec and cancer ranked a distant second at 22 %. Currently, these two causes of death are nearly tied, Circulatory diseases are now responsible for 34 % of all deaths and cancer for 30 %. Since Quebec's population is expected to continue aging for the next few decades and because the incidence of cancer increases with age, it is likely that cancer will soon become the leading cause of death.

The direct and indirect costs associated with the potential years of life lost because of cancer, early detection, diagnosis and treatment, and palliative care for the dying are very high and will continue to climb.

Quebec's cancer control program clearly shows the importance of evaluating cancer control activities and introducing surveillance mechanisms to monitor past and future progress. The program is underpinned by a strategic planning process that includes a realistic assessment of the needs, resource requirements and priorities related to reducing cancer's impact on the people of Quebec. Health indicators for cancer control activities are essential to guiding the surveillance process and assisting in decision-making.

Cancer survival is one of the main health indicators, along with incidence (number of new cases each year) and mortality. Changes in survival are an indication of the evolution in the fight against cancer. Survival is also used to measure the effectiveness of treatment and early detection, to evaluate various detection methods and to make comparisons with other provinces and other Western countries.

The main purpose of this study is to describe the quality of the data used to calculate survival in Quebec. The discussion will focus on the quality of incidence and mortality data, the kind of file linkage needed to determine a person's vital status, and the influence that this data quality has on survival results. This study is also part of a Canada-wide initiative to quantify cancer survival. Statistics Canada and the Canadian Cancer Survival Analysis Group have produced a Canadian Cancer Survival Protocol. To facilitate comparison, the protocol used in this survival study is largely based on the Canadian protocol.

Survival for new 1992 cancer cases in Quebec was measured so that the results could be compared with Statistics Canada's recent findings, which also included new cases for 1992 by province of residence. Similar survival tables for cases of cancer diagnosed between 1984 and 1998 will be prepared at a later stage.

#### 2. PURPOSE

- > To describe the quality of the data used to calculate survival in Quebec.
- To calculate age-standardized five-year relative survival rates for new cases reported in the Quebec cancer registry (Fichier des tumeurs du Québec) in 1992.
- > To compare age-standardized five-year relative survival rates in Quebec and other Canadian provinces.

#### 3. METHOD

### 3.1. Target population and eligibility criteria

The analysis focused on the leading sites of cancer in adults, based on the International Classification of Diseases, Ninth Revision (ICD-9), topography: prostate cancer (ICD-9; code 185), breast cancer in women (ICD-9; code 174), lung cancer (ICD-9; code 162) and colorectal cancer (ICD-9; code 153 and code 154).

The population covered in this study consists of adults who were between the ages of 15 and 99, inclusive, at the time of the diagnosis, and for whom the diagnosis of a malignant tumour, excluding skin cancer other than melanoma, was reported in 1992 for the first time. Non-melanoma skin cancer cases were excluded because this type of cancer is largely under-reported to the Quebec cancer registry. Individuals for whom another primary cancer had been reported prior to 1992 were also excluded. Second primary cancer sites reported in 1992 were not considered. Also, all individuals who had left Quebec and whose departure date was unknown were excluded.

Records with incomplete or missing information concerning gender, year of birth, year of diagnosis, year of death (for individuals known to be deceased), site, morphology and behaviour were excluded. Also excluded were non-residents of Quebec, persons whose gender was incompatible with the site, and records in which the date of diagnosis preceded the date of birth or followed the date of death.

### 3.2. Method used to estimate survival

Survival was calculated for a maximum of five years between the first event, which is the known date of diagnosis in 1992, and the second event, which is death. The study's end date was December 31, 1997.

The relative survival method was used in this analysis. This method is the most commonly used for creating survival tables. The relative survival rate is defined as the ratio of the observed survival rate for a patient study group to the expected survival rate for the general population presenting the same characteristics as the study group at the beginning of the study period.

The observed survival rates are based on incidence and death data, while the expected survival rates are deduced from mortality tables for the general population by single years of age (0-99) covering the same period. The mortality tables are based on 1991 mortality and population data by single years of age up to 99; the mortality data were provided by the Ministère de la Santé et des Services sociaux, and the population data by the Institut de la statistique du Québec.

Various software packages used to calculate survival were tested by Statistics Canada. The following two packages yielded similar results and were recommended: the Strel module with the STATA package and SEERstat. The former is based on Estève's (Estève *et al.* 1990) estimation method and the latter on Hakulinen's (1982) estimation method. This study used the Hakulinen method.

Age-standardized survival rates were also computed. Standardized survival rates can be compared directly. Age-standardized relative survival rates are the weighted sum of relative survival rates for specific age groups (Coleman et al., 1999). The reference "populations" used were the age-specific numbers of new cancer cases for each cancer site in the study for all Canadian provinces except Quebec. The reference population used for the Statistics Canada study on survival in Canada was used in this study for comparison purposes.

#### 3.3. Incidence and mortality data

The survival rate is based on incidence and mortality data. The following data are needed to estimate this indicator: the date of birth, date of diagnosis, date of death (if applicable), site, morphology, behaviour, identification of first invasive primary cancer, indicator of departure from Quebec (if applicable), vital status and gender.

#### 3.3.1. Incidence data

Data on the incidence of cancer cases diagnosed and reported in Quebec in 1992 come from the Quebec Tumours File (QTF). Currently, only hospitalization and day surgery records are reported to the QTF. Cancers diagnosed in a physician's office and treated on an out-patient or ambulatory basis are not reported in the file. Today, owing to simpler diagnostic methods and less invasive surgical procedures, certain tumours that are easily accessible or caught at an early stage can be diagnosed and fully treated without hospitalization or day surgery. Such cases are never reported to the QTF or will only be reported at a more advanced stage of the disease, when hospitalization is required. The magnitude of the under-declaration phenomenon by cancer site generated by this new situation is not yet known.

The fact that the real date of diagnosis is not always available constitutes a factor in survival underestimation. It is also important to note that the discharge date following the first hospitalization for cancer is assumed to be the reporting date. As will be seen later, this may create another bias in the interpretation of survival.

#### 3.3.2. Death data from the Quebec Deaths File

The Quebec Deaths File (QDF) is a demographic record of all deaths in Quebec. Linking the QTF with the QDF is essential to determining the vital status of persons with cancer. However, as reported in an earlier study of cancer survival by the Ministère de la Santé et des Services sociaux (Pelletier, G. 1993), the QDF is not complete enough to identify all cancer patient deaths.

#### 3.3.3. <u>Death data from the "fichier d'inscription des personnes assurées"</u>

The subscriber file (FIPA) of the Régie de l'assurance maladie du Québec (RAMQ) has proven to be an important complementary source for identifying deaths not reported in the QDF and determining whether a person has been removed from the insured list because he or she has left Quebec (Pelletier, G. 1993).

#### 3.4. File linkage

The types of linkages made require special mention because they have a significant impact on the results. The validity of the survival indicator depends on our ability to fully and precisely identify the vital status of the individuals being studied. File linkage is based on nominative variables required to identify the subjects.

#### 3.4.1. Linkage of the Tumours and Deaths files

Linkage is performed with SAS using SQL procedure. The nominative variables needed to match the Tumours and Deaths files are: the health insurance number (HIN), date of birth, gender, name at birth, given name, mother's surname and father's given name. Individual manual validation is done for uncertain matches, that is, cases where the full surnames and given names are not identical in both files. Other variables are then used to ascertain whether the two records referred to the same person: postal code, municipal and CLSC area of residence, diagnosis or cause of death, date of death, date of diagnosis, hospital and CLSC.

Initially, the HIN was used as a match key between the Tumours Deaths files. The HIN is a unique alphanumeric identifier and the RAMQ assigns one to each person in Quebec. It has the following structure: the first three positions are the first three letters of the person's surname at birth, the fourth position is the first letter of the given name, the fifth to tenth positions consist of the date of birth and gender and the eleventh and twelfth positions are used for checking information. For matches where the HIN was not identical, the first ten positions were compared. Matches of this type were done manually.

For records where the HIN was not in the Deaths File, a variable identical to the HIN's first ten positions was generated by taking the first three letters of the surname, the first letter of the given name, the date of birth and gender. This variable was matched against the first ten positions of the HIN in the QTF. This type of match was also checked manually using the complementary information described above. Failed matches were deleted from the match file.

It should also be noted that in all of our linkage scenarios, only the HIN, the HIN's first ten positions and a variable generated by taking the first three letters of the surname, the first letter of the given name, the date of birth and gender were used. Other wider linkage criteria were previously tested but yielded no better results.

#### 3.4.2. Linkage between the QTF and the FIPA

Lastly, incident cancers reported in the QTF were linked with the FIPA to identify deaths and ascertain whether a person had been crossed off the insured population because he or she had left the province of Quebec. This matching was done by the RAMQ. It consisted of one level of linkage based on a perfect match between the HINs in both files.

#### 4. **RESULTS AND DISCUSSION**

#### 4.1. Target population and eligibility criteria

Among the 32,961 new cases reported in 1992 in Quebec, 4,041 did not have an invasive tumour (Cim-9 140 to 208 except 173), 2,680 did not have a first primary tumour and 245 did not meet the criterion of 15 to 99 years of age. Table 1 shows the number of cases retained for analysis (25,995) following the application of the exclusion criteria.

#### Table 1: Number of New Cases Covered, by Exclusion Criterion, Quebec, 1992

Exclusion Criterion	Number Remaining After Application of Exclusion Criteria				
All tumours (ICD-9 140-239)	32,961				
Invasive tumours (ICD-9 140-208 except 173)	28,920				
First tumour only	26,240				
Age at diagnosis (15-99 inclusive)	25,995				

#### 4.2. Linkage results

#### 4.2.1. Linkage between the QTF and the QDF

Although the analyses were carried out for 1992, linkages were done on new cancer cases recorded in the Quebec Tumours File between 1975 and 1998 and Deaths File from 1975 to 1999. In fact, this analysis was part of a research study on cancer survival from 1984 to 1998. The results are shown in Table 2. Records with identical HINs were not checked manually. Similarly, records for which the first ten positions of the HIN in the QDF matched the first ten positions of the HIN in the QTF and for which the surname and given name matched were not validated by hand. A manual check was done for matches relating to new cases in 1992, and all 1,133 records with these characteristics were retained (see Table 2). This represents about 8 % of the new cases for 1992 which became deaths within five years following the diagnosis.

	Number of Cases Matched	Number of Case After Manual	es Retained Validation
HIN present in the QDF		Number	0⁄0
Identical HINs	286,697	286,697 <sup>2</sup>	100.0
HINs not identical, but first 10 positions of HINs, surnames and given names identical	4,998	4,975	99.5
HINs and surnames not identical, but first 10 positions of HINs and given names identical	920	330	35.9
HINs and given names not identical, but first 10 positions of HINs and surnames identical	2,437	870	35.7
HINs, surnames and given names not identical, but first 10 positions of HINs identical	4,728	91	1.9
HIN missing in the QDF			
First 10 positions of HIN in the QTF and 10- position HIN formed from QDF along with surnames and given names identical	528,473	528,4732	100.0
First 10 positions of HIN in the QTF and 10- position HIN formed from QDF along with surnames and given names identical for 1992	1,133	1,133	100.0
Surnames not identical, but first 10 positions of HIN in the QTF and 10-position HIN formed from QDF along with given names identical	21,802	21,032	96.5
Names not identical, but first 10 positions of HIN in the QTF and 10-position HIN formed from QDF along with surnames identical	58,928 <sup>3</sup>	57,835 <sup>3</sup>	98.2
Surnames and given names not identical, but first 10 positions of HIN in the QTF and 10- position HIN formed from QDF identical	10,784	4,235	39.3

Table 2 :Results of Matching New Cancer Cases Reported in the Quebec Tumours File for1975 to 1998 Against the Quebec Deaths File for 1975 to 19991

<sup>1</sup> The 1999 Deaths File is still incomplete at the moment of the linkage. Deaths in Ontario and trauma cases requiring a Coroner's inquest are missing.

<sup>2</sup> Manual validation not required.

<sup>3</sup> Only records with a diagnosis date of 1984 or later were validated, out of a total of 97,574 records that met this criterion.

#### 4.2.2. Deaths among new cases according to the source of information

Of the 25,995 new cases of cancer that were reported in the Tumours File for 1992 and included in the survival study, 15,069 died before January 1, 1998. Of those deaths, 2 % were identified exclusively with the FIPA and 1 % were found exclusively in the QDF. When FTQ death information was not considered, these proportions rose to 4 % and 5 %, respectively, in the FIPA and QDF. Thirty-five deaths were traced exclusively in the QTF. This last finding probably indicates that those cases were not identified through linkage of the QTF with other death data files. Table 3 shows the number and percentage of deaths found in each of our three data sources. In addition, individuals who left Quebec were excluded from the study because information about their vital status was unavailable. There were about 150 such cases.

## Table 3:Sources of Data on Deaths in Cases Diagnosed in 1992 and Deceased Before<br/>January 1, 1998

Vital status	Number	Percentage
From QTF	35	0.30
From QDF	161	1.07
From FIPA	344	2.28
From QDF and FIPA	4,384	29.07
From QTF and FIPA	274	1.82
From QDF and QTF	538	3.57
From FIPA, QTF and QDF	9,333	61.89
Total	15,069	100.00

Thus, it appears that the Quebec Deaths File alone is not sufficient for identifying all deaths in the Quebec population. The same is true of the FIPA. It should be noted that the QTF contains approximately 68 % of all deaths.

#### 4.3. Quality of the data used to calculate survival duration

In the QTF, the date of diagnosis is defined as the date of discharge following the first hospitalization during which the cancer diagnosis is mentioned. Clearly, in many situations that date is not the cancer's actual onset date. The diagnosis may have been made earlier, before the progress of the disease made hospitalization necessary. With some cancers, diagnosis and treatment never require hospitalization. In such cases, patients who have the potential to live longer are excluded from both the numerator and denominator of survival probability. In other situations, patients are not hospitalized for the first time until the very end. Ultimately, regardless of the reason, all factors contributing to the actual time of diagnosis being unknown because of our data source have the same effect: the underestimation of the duration of survival.

#### 4.3.1. Zero day survival duration

A person who goes into hospital for the first time because of cancer and dies there will be assigned a date of diagnosis equal to the date of death, which is a survival duration of zero. In fact, zero survival duration was found in 10 % of new diagnosed cases reported in 1992. This proportion varies according to cancer site and gender. Lung cancer has the highest proportion. Of the new cases of lung cancer in 1992, the zero survival proportions were 20 % for males and 18 % for females. For colorectal cancer, they were 7 % for males and 10 % for females. They were 2 % for breast cancer in women and 3 % for prostate cancer (see Table 4).

Obviously, the percentages of zero survival cases by site are larger for deaths (see Table 4) than for incidence, and change with cancer site. In fact, the size of the difference between the proportion of zero-survival cases among new cases and the proportion among deaths varies by cancer site. For lung cancer, the difference is about 3 percentage points among men and 4 percentage points among women, compared with about 6 for breast cancer , 4 for prostate cancer , 5 for colorectal cancer in men and 7 for colorectal cancer in women. In short, differences observed for lung cancer among both men and women are lower than differences computed for other cancer sites.

	Number of	Cases <sup>1</sup>		N	Variation			
Cancer Site/ Gender	Total Numbers	Numbers % (N) After Exclusion of Zero Survival		Total Numbers	Numbers After Exclusion of Zero Survival	% (N)	PP <sup>3</sup>	
Men								
Prostate	2,766	2,686	2.9 (80)	1,090	1,010	7.3 (80)	4.4	
Lung	3,184	2,607	18.1 (577)	2,763	2,186	20.9 (577)	2.8	
Colorectal	1,832	1,714	6.4 (118)	1,053	935	11.2 (118)	4.8	
Women			· · · · ·					
Breast	3,651	3,561	2.5 (90)	1,033	943	8.7 (90)	6.2	
Lung	1,451	1,201	17.2 (250)	1,202	952	20.8 (250)	3.6	
Colorectal	1,793	1,627	9.3 (166)	1,008	842	16.5 (166)	7.2	

Table 4 :	Proportion of New Cancer Cases Reported in 1992 and of Deaths Having a
	Survival Equal to Zero According to the Cancer Site and Gender

<sup>1</sup> New cases retained for survival study

<sup>2</sup> Within first five years of follow-up

<sup>3</sup> Differences in percentage points

Because of the high proportion of new cases with zero survival, the duration of hospitalization for individuals prior to their deaths was examined. We found that, in fact, 75 % of them were in hospital for at least nine days before death, 50 % for at least 20 days, and 25 % for at least 41 days, and only 5 % actually died the day they were admitted or the following day. The date of death was equal to the date of admission in only 1 % of cases (see Table 5). In fact, the use of the discharge date following the first cancer-related hospitalization was responsible for the very large proportion of cases with zero survival recorded in the QTF, compared to other provinces. However, when the admission ddate was used as the date of diagnosis, zero survival was found in only 0.1 % of all new cases.

Number of Days	Cumulative Frequency
≥3	90
≥9	75
≥ 20	50
≥ 41	25
≤1	5
= 0	1

Table 5 : Number of Days Between Hospital Admission Date and Discharge Date (Official<br/>Date of Diagnosis) for New Cases reported in 1992 with a Survival Duration of<br/>Zero

#### 4.3.2. <u>Underreporting</u>

The underreporting of cases in the QTF is another factor affecting the calculation of the duration of survival. It could depend on the type of cancer and the possibility of detecting and treating it in a doctor's office or on an out-patient basis. Skin cancer other than melanoma is a good illustration of this point. It is clearly underreported because that it is often detected and treated on an out-patient basis. Moreover, this is the reason it is consistently excluded from analyses into the incidence of cancer, mortality by cancer and survival with cancer. Thus, the more cancer treatment and follow-up there is in out-patient facilities the more the cancer in question is underreported to the QTF. A similar situation prevails for the sites of cancer under study. Nevertheless, the impact of this underreporting on the probability of survival depends on the linkage between survival duration and the cancer site. For instance, the impact of underreporting in the case of lung cancer could be less significant than that in the cases of prostate cancer considering that the short duration of survival, the severity of morbidity and the treatment of lung cancer require hospitalization.

#### 4.3.3. Impact of additional death data from FIPA

We also found that the 2 % of additional deaths identified through linkage with the FIPA were essential for a more accurate interpretation of survival, as was the exclusion of people who had left Quebec at an unknown date during the study. The addition of 2 % of deaths from a data source other than the Deaths File reduced the probability of survival (see table 6). However, this decrease depends on the cancer site. Indeed, the difference observed varies from 1 to 3 percentage points.

	Informati from Q	on on Deaths an uebec Drawn fron Excluded	d Departures m the FIPA	Information on Deaths and Departures from Quebec Drawn from the FIPA Included			
Gender/Cancer site	Rate	Number of Number of cases deaths <sup>1</sup>		Rate	Number of cases	Number of deaths <sup>1</sup>	
Male	%			%			
Prostate	86	2,695	967	83	2,686	1,010	
Lung	22	2,546	2,081	20	2,607	2,186	
Colorectal	60	1,708	889	57	1,714	935	
Female							
Breast	82	3,575	908	81	3,561	943	
Lung	25	1,194	924	23	1,201	952	
Colorectal	61	1,622	801	58	1,627	842	

Table 6:Number of New Cases and Deaths, Excluding Cases Presenting Survival Equal to<br/>Zero, According to the Inclusion or Exclusion of Information on Deaths and<br/>Departures from Quebec Drawn from the RAMQ's FIPA

<sup>1</sup> Within first five years of follow-up

#### 4.4. Results

Survival equal to zero could be an indicator of the underreporting of new cases with the FTQ and since its impact on the results has not been studied yet, it becomes interesting to also examine the probabilities of relative survival by excluding the cases with zero-survival. Thus, in the following section, two results on the probabilities of survival are presented; the first includes people with zero-survival duratrion and the second excludes these cases.

#### 4.5. Five-year relative survival rate by age group for each cancer site

Five-year relative survival for prostate cancer in Quebec is lower among the younger segment of the population (15-54). There is a 16 percentage point difference between survival in that group (72 %) and survival in the 55-64 age group (88 %) (see table 7). We also found that prostate cancer survival declines with age. No matter which method is chosen (zero survival included or excluded), the difference between relative survival rates is significant. It is worth noting that prostate cancer can be treated on an out-patient basis. Underreporting could be quite substantial, which may explain the differences observed.

For breast cancer in women, the 40-49 age group has the highest five-year relative survival, at about 83 %. The rates are very similar in the 60-69 age group (82 %). Survival is lowest in the 15-39 and 80-99 age groups, at 75 % and 71 % respectively. Five-year survival for breast cancer in women is generally stable in the 40-49 and older age groups; it rises and falls slightly from one age group to the next. Exclusion of the zero-survival cases does not change the age-specific relative rates appreciably (0 to 2 percentage points higher), except in the 80-99 group, where the rate is 9 percentage points higher. According to Table 7, the relative survival rates for breast cancer are stable for all age groups. The 9 percentage-point difference in the 80-99 age group suggests that underreporting and zero-survival, which may affect new cases of breast cancer, are more common for persons in this group since they are elderly, their life expectancy is nearly zero and, therefore, they are hospitalized early.

Five-year survival following diagnosis of colorectal cancer declines with age for both men and women. The best survival rates are found in the 15-49 age group, with 58 % for males and 63 % for females. The difference between the youngest group (15-49) and the oldest group (80-99) is 14 percentage points for males and 18 for females. The difference between the relative survival rates, according to inclusion or exclusion of the cases with zero-survival, for this cancer site, varies from 1 to 3 percentage points for the 15-69 age group and from 6 to 12 percentage points for the 70-99 age group. As in the case of breast cancer, these differences could reflect the fact that underreporting and zero-survival are more common among the elderly since their life expectancy is low and they are hospitalized more.

As previously noted, lung cancer has the lowest relative survival rates. It is the worst killer of all cancers. Five years after diagnosis, a mere 17 % of new cases are still alive among males aged 15 to 49 and 23 % among women in the same group. Relative survival for lung cancer also decreases with age in both men and women. It is 9 % for both sexes in the 80-99 age group, which is 8 percentage points lower than the rate for males in the 15-49 age group and 14 points lower than the rate for females in the same group. Because the morbidity and treatments for lung cancer are so severe, a large percentage of people with lung cancer may be hospitalized. In addition, survival duration may be underestimated less since survival is very short for this type of cancer. The underreporting problem also affects this type of cancer to a lesser degree. Excluding the zero-survival cases merely overestimates the actual relative survival rates (see Table 7).

	Includ	ling the cases	whose survi	val is equal	Excluding	g the cases wh	ose surviv	al is equal
		<b>0-</b> 0/	to zero			to ze	ro	
Cancer site/ Age group	Rate	95 % Confidence interval	Number of cases	Number <sup>1</sup> of deaths	Rate	95 % Confidence interval	Number of cases	Number <sup>1</sup> of deaths
Male								
Prostate								
15-54	72	(61-83)	73	22	72	(61-83)	73	22
55-64	88	(84-92)	550	108	89	(85-93)	544	102
65-74	86	(83-89)	1,184	366	87	(84-90)	1,167	349
75-84	71	(65-77)	782	447	75	(69-81)	743	408
85-99	53	(36-70)	177	147	59	(40-78)	159	129
15-99	82	(78-85)	2,766	1,090	83	(81-86)	2,686	1 010
Colorectal		· · ·	-			× ,		
15-49	58	(50-66)	152	65	59	(51-67)	150	63
50-59	52	(46-58)	292	149	53	(47-59)	288	145
60-69	55	(50-60)	575	298	57	(52-62)	554	277
70-79	54	(48-60)	557	340	60	(54-66)	504	287
80-99	44	(33-55)	256	201	56	(43-69)	218	163
15-99	54	(51-57)	1.832	1.053	57	(54-60)	1.714	935
Lung		()	_,	_,		(• - • • •)		
15-49	17	(12-22)	204	170	18	(12-24)	189	155
50-59	18	(12-22)	542	451	20	(12 24) (16-24)	478	387
60-69	18	(16-20)	1 166	986	20	(18-24)	990	810
70-79	15	(12-18)	954	853	19	(17-22)	743	642
80-99	9	$(12 \ 10)$	318	303	15	(17 22) (8-23)	207	192
15-99	16	(15-18)	3.184	2.763	20	(17-23)	2.607	2.186
Female	10	(10 10)	0,101	_,, 00	20	(17 =0)	2,007	_,100
Broast								
15 20	75	(70.80)	252	65	75	(70.80)	253	65
10-39	83	(80.86)	255	124	75 83	(80.86)	699	123
40-49 50 50	70	(76.82)	700	124	80	(77.82)	705	123
50-59 60 69	82	(70-82)	802	212	83	(80.86)	879	104
70.79	78	(79-83)	726	212	80	(75.84)	699	232
80.99	70	(74-02) (62.80)	368	239	80	(73-64) (71.89)	326	170
15 99	71	(02-00) (77.81)	3 651	1 033	81	(71-09) (79.83)	3 561	943
Coloroctal	19	(77-01)	5,051	1,033	01	(79-03)	5,501	243
15 40	62	(EE 71)	140	EE	6 E	(57.72)	145	ED
13-49	65 E0	(55-71)	140	33	65	(57-75)	143	52
50-59	59 52	(32-66) (48 E8)	194	82 221	60 E6	(55-67) (51-61)	191	208
00-09 70 70	55	(40-50)	400	231	56	(51-61)	437	206
70-79 80.00	51 45	(40-30)	334 427	225	57	(32-62)	493	236
00-99 15 00	43	(50-52)	437	323	54	(40-02) (EE 61)	1 6 2 7	247
15-99 I	55	(50-56)	1,793	1,008	58	(55-61)	1,627	842
Lung	22	(17.00)	104	140	25	(10.01)	170	10.4
15-49	23	(17-29)	194	149	25	(19-31)	179	134
50-59	21	(16-26)	309	247	23	(18-28)	273	211
60-69	21	(17-25)	441	353	25	(21-30)	382	294
70-79	15	(11-19)	366	319	20	(15-25)	280	233
80-99	9	(3-15)	141	134	14	(4-24)	87	80
15-99	19	(17-21)	1,451	1,202	23	(17-21)	1,201	952

## Table 7:Five-year Relative Cancer Survival Rates for Cases Reported in 1992 in Quebec, by<br/>Site and Age Group, Including Zero-survival Cases

<sup>1</sup>Within the first five years of follow-up.

#### 4.6. Age-standardized site-specific relative survival rates

Prostate and breast cancer have the highest age-standardized relative survival rates. Including zero-survival cases, the rate of survival five years after diagnosis is about 79 % for each one. The five-year survival rate for colorectal cancer ranks second, at about 52 % for males and 53 % for females. Lung cancer has the lowest survival rate of all major cancers, with rates of 16 % for males and 18 % for females (see Table 8).

# 4.7. Comparison of five-year relative survival rates in Quebec and other Canadian provinces

Statistics Canada recently published age-standardized five-year relative survival rates for new cancer cases reported in 1992 for the provinces and Canada excluding Quebec (*Ellison et al.* 2001). Comparisons included the following provinces: Newfoundland, Nova Scotia, New Brunswick, Ontario, Manitoba, Saskatchewan, Alberta and British Columbia. Even though the same case eligibility criteria were used throughout Canada, Statistics Canada had difficulty comparing survival in Quebec with survival in other provinces. Consequently, Quebec's relative survival rates were presented separately. The main reasons for this decision are as follows: the definition of the date of diagnosis in the Quebec Tumours File is different from the definition used in the other provinces and does not reflect the real date of diagnosis; the high proportion of people with a survival equal to zero days (10 %) is not comparable with the remainder of Canada (0.3 %), and the QTF is based solely on hospitalized cases.

Having computed survival tables for Quebec, we think that survival in Quebec is probably underestimated. Moreover, the addition of another complementary source to determine deaths in Quebec led to a better estimate of survival. However, this estimate is weaker if, in the other provinces, the official Declarations of Deaths files is insufficient (as in Quebec) and if it is the only source used to determine the vital status of the new cases. For provinces with rates lower than Quebec's, comparisons are easy. We know that even though Quebec rates are underestimated, they are higher. However, for provinces with higher rates, depending on the cancer site, underreporting of new cases in the QTF and the additional 2 % of deaths should be taken into consideration.

Notwithstanding the underestimation of survival in Quebec, Table 8 provides a comparison of the relative survival rates in Quebec according to the inclusion or exclusion of zero-duration survival and the rest of Canada. However, only the probabilities of comparative relative survival for the new cases including the people with zero-survival will be commented on. In fact, the actual cancer survival rate in Quebec for cancers with a long survival duration is somewhere above the rates based on data that include zero-duration survival cases, which implies an understatement of actual survival. The decision to present survival rates that include zero-duration survival cases is a conservative choice. We made that choice, fully aware that the resulting survival rates are minimum thresholds below the actual rates.

The age-standardized five-year relative survival rate for prostate cancer in Quebec is 79 %, that is to say a probability comparable to that of several provinces when one takes the confidence intervals into account, with the exception of Ontario and British Colombia. The age-standardized relative rate for breast cancer in women is 79 % in Quebec. It is lower in Newfoundland and New Brunswick and the same in Manitoba. The estimated age-standardized relative survival rate for colorectal cancer in males is higher in Quebec than in New Brunswick. The corresponding rate for women is the same in Quebec as in New Brunswick.

Even though lung cancer has more such cases with zero-duration survival than the other cancer sites studied in Quebec (about 20 % of the cases) but is less affected by them, its age-standardized relative survival rate for males is higher in Quebec (16 %) than in any other province (see Table 9). The corresponding rate for women in Quebec is the same as in Ontario (18 %) but higher than in all other provinces except Newfoundland (20 %).

		Ν	Iale		Female			
Cancer site/ Province	Rate	95 % Confidence interval	Number of cases	Number <sup>1</sup> of deaths	Rate	95 % Confidence interval	Number of cases	Number <sup>1</sup> of deaths
Prostate/Breast								
Canada	87	(85-88)	11,289	3,929	82	(81-83)	11,008	2,850
Newfoundland	67	(55-77)	133	65	76	(68-82)	217	64
Nova Scotia	82	(75-87)	445	172	84	(79-88)	456	110
New Brunswick	83	(76-89)	408	145	77	(71-82)	345	102
Ontario	86	(84-88)	5,363	1,889	82	(81-83)	5,688	1,468
Manitoba	85	(80-89)	842	314	79	(74-83)	580	176
Saskatchewan	83	(77-87)	621	230	83	(78-86)	550	147
Alberta	82	(78-85)	1,084	405	81	(78-84)	1,203	307
British Columbia	91	(88-93)	2,304	669	85	(83-87)	1.884	447
Quebec (0 survival included)	79	(78-80)	2,766	1,090	79	(78-80)	3,651	1,033
Quebec (0 survival excluded)	81	(81-82)	2,686	1,010	81	(80-82)	3,561	943
Colorectal								
Canada	56	(54-58)	5,358	2,940	59	(58-61)	4,505	2,276
Newfoundland	56	(46-66)	145	75	56	(46-65)	135	66
Nova Scotia	54	(45-62)	237	135	56	(49-63)	243	128
New Brunswick	47	(39-55)	192	111	52	(43-60)	178	99
Ontario	55	(53-58)	2,831	1,564	59	(57-61)	2,339	1,191
Manitoba	53	(46-60)	303	170	60	(53-66)	284	139
Saskatchewan	54	(46-61)	256	144	65	(56-72)	190	87
Alberta	54	(48-59)	503	283	55	(49-60)	379	204
British Columbia	59	(54-63)	842	426	61	(56-65)	705	335
Quebec (0 survival	50		1 000	1 052	52		1 700	1 000
included)	52	(49-56)	1,832	1,055	55	(50-55)	1,795	1,008
Quebec (0 survival excluded)	57	(54-61)	1,714	935	57	(54-60)	1,627	842
Lung								
Canada	14	(13-15)	6,853	6,061	17	(16-18)	3,929	3,314
Newfoundland	13	(8-20)	136	121	20	(10-33)	50	42
Nova Scotia	13	(10-17)	334	297	16	(11-23)	169	143
New Brunswick	15	(11-20)	296	259	11	(6-17)	143	129
Ontario	15	(14-16)	3.765	3.290	18	(17-20)	1.065	1.714
Manitoba	15	(11-20)	371	325	15	(10-20)	217	187
Saskatchewan	8	(6-12)	320	267	17	(12-23)	174	146
Alberta	10	(7-13)	607	557	13	(10-17)	374	323
British Columbia	12	(10-15)	967	862	15	(12-18)	699	598
Quebec (0 survival included)	16	(14-18)	3,184	2,763	18	(16-20)	1,451	1,202
Quebec (0 survival excluded)	19	(17-22)	2,607	2,186	23	(19-25)	1,201	952

## Table 8 : Age-Standardized Five-year Relative Survival Rates for Cancer Cases Reported in1992 by Site, Gender and Province

<sup>1</sup>Within the first five years of follow-up.

#### 5. CONCLUSION

The survival indicator is based primarily on the vital status of the cases reported. Vital status is not reported systematically in the Tumours File. It must be determined by matching the Tumours File against the Deaths File. Unfortunately, the Deaths File is not sufficient. A supplementary linkage with the administrative file of RAMQ subscribers shows that about 4 % of the new cases being studied died in the five years following diagnosis without being recorded in the Deaths File and that half of these were reported only in the FIPA, while the other half were reported in both the FIPA and the QTF. If we limited ourselves only to deaths drawn from the Deaths File, these unrecorded cases would be considered still alive, and survival would be overestimated as a result.

We have also noted that the linkage criteria are very important factors in determining the vital status of reported cases, since the HIN is not always recorded in the Deaths File. In general, Quebec's age-standardized five-year relative survival rates for the major cancer sites are comparable to those in other provinces even though survival duration in Quebec is possibly underestimated as a result of two significant problems. First, the number of new cancer cases is underestimated in the Tumours File because only hospitalized cases and cases treated in day surgery are recorded. Cases diagnosed and treated entirely on an out-patient basis are missing or reported at a more advanced stage of the disease when hospitalization is required. Second, the date of diagnosis in the Tumours File is the date of discharge following the first hospitalization for cancer. These two problems complicate the comparison of survival with other parts of Canada.

The underreporting problem and the survival duration problem could be largely remedied if the Tumours File managers had access to the reports of the laboratories that analyze fluid and tissue samples and confirm pathologies and diagnoses. This solution would not only capture all tumour cases but would also provide accurate data on the diagnosis and actual date of diagnosis.

Also, awareness of the magnitude of underreporting and the characteristics of cases unreported in the QTF as well as of their probability of survival would help to correct and improve the underestimation of survival in Quebec. Our results lead us to believe that hospitalization depends on the morbidity and gravity of the cancer, on duration of survival and on the age of the cancer patient. Therefore, cases not hospitalized and consequently not reported to the QTF are probably those of relatively young people who present a type of cancer with a relatively long survival duration.

#### 6. **REFERENCES**

BEAUPRÉ, Michel. *Surveillance du cancer au Québec de 1992 à 1998*, Quebec, ministère de la Santé et des Services sociaux, 2002.

BOUCHARD, Clermont and Rabia LOUCHINI. *Surveillance de la mortalité au Québec, 1976 à 1998,* Quebec, ministère de la Santé et des Services sociaux, 2001.

BRISSON, Jacques and Diane MAJOR. *Plan de surveillance de la lutte contre le cancer du sein*, Quebec, ministère de la Santé et des Services sociaux, 2000.

COLEMAN, M.P. *et al.* "Cancer Survival Trends in England and Wales 1971-1995: Deprivation and NHS Region". *Series SMPS*, no. 61, London, the Stationery Office, 1999.

COMITÉ CONSULTATIF SUR LE CANCER. *Programme québécois de lutte contre le cancer*, Quebec, ministère de la Santé et des Services sociaux, October 1997.

ELLISON, Larry F., Laurie GIBBONS and le GROUPE D'ANALYSE DE LA SURVIE AU CANCER AU CANADA. *"Taux relatifs de survie à cinq ans – cancers de la prostate, du sein, du côlon et du rectum, et du poumon"*. Rapports sur la santé, vol 13, no. 1, December 2001, p. 25-34.

ESTÈVE et al. Relative Survival and the Estimation of Net Survival: Elements for Further Discussion. Stat Med 1990; 9: 529-538

HAKULINEN T. Cancer survival corrected for heterogeneity in patient withdrawal. Biometrics, 38:933-942, 1982

PELLETIER, G. La survie reliée au cancer; Étude des nouveaux cas déclarés au Québec au cours des années 1984, 1985 et 1989, Quebec, ministère de la Santé et des Services sociaux, 1993.