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### New Associate Scientific Editor

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**New Associate Scientific Editor**

We are very pleased to announce and welcome a new Associate Scientific Editor to the editorial staff of *Chronic Diseases in Canada*, Dr Robert A Spasoff. He is a full-time Professor at the University of Ottawa's Department of Epidemiology and Community Medicine.



# *Agreement in Measuring Socio-economic Status: Area-based Versus Individual Measures*

Kitaw Demissie, James A Hanley, Dick Menzies, Lawrence Joseph and Pierre Ernst

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## **Abstract**

*Area-based socio-economic status (SES) measures are frequently used in epidemiology. Such an approach assumes socio-economic homogeneity within an area. To quantify the agreement between area-based SES measures and SES assessed at the individual level, we conducted a cross-sectional study of 943 children who resided in 155 small enumeration areas and 117 census tracts from 18 schools in Montreal, Quebec. We used street address information together with 1986 census data and parental occupation to establish area-based and individual level SES indicators, respectively. As compared with the SES score determined at the level of the individual, 13 different area-based SES indices classified the children within the same quintile 28.7% ( $\pm 2.8\%$ ) of the time. The discrepancy was within one quintile in 35.3% ( $\pm 2.3\%$ ) of cases, two quintiles in 20.6% ( $\pm 3.6\%$ ), three quintiles in 11.3% ( $\pm 4.2\%$ ) and four quintiles in 4.1% ( $\pm 0.2\%$ ). In conclusion, we observed a substantial discrepancy between area-based SES measures and SES assessed at the individual level. Caution should therefore be used in designing or interpreting the results of studies in which area-based SES measures are used to test hypotheses or control for confounding.*

**Key words:** contextual variables; cross-level bias; ecological variables; etiologic research; small area; socio-economic status

## **Introduction**

Individual health outcomes may have individual and aggregate (environmental) level determinants. Cross-level bias is a phenomenon whereby inference about one level of analysis is made on the basis of associations observed at a different level.<sup>1</sup> The most commonly discussed cross-level bias in epidemiology is “ecological fallacy,” which is the result of improper interpretation and inference about individual level associations based on associations at the aggregate level.<sup>2,3</sup> Analyses that relate aggregate characteristics to individual outcomes do not necessarily result in ecological bias.<sup>1</sup>

In surveys, socio-economic status (SES) may be a sensitive issue for an individual, and this may impair the practicality and validity of direct questions concerning various attributes of SES.<sup>4</sup> An alternative approach is to use indirect information based on average values of social and economic conditions for geographic areas of residence. In addition to the advantage of limiting

non-response, this area-based approach is relatively inexpensive, and information is readily accessible.

In etiologic research, the health outcome may be collected at the level of the individual, while the exposure characteristics, such as SES attributes, are collected at the level of geographic area to test the hypothesis that SES is associated with a particular health outcome or to control for confounding by SES.<sup>5-13</sup> Various area-based attributes of SES have been used—for example, average house value, median monthly rental value of dwellings and the proportion of university-educated subjects, single-parent families or unemployed people as well as composite scales formed by combining these variables.<sup>7,8</sup> This approach is based on an assumption that the characteristics are stable and homogeneous within the geographic area. However, in urban areas the population can be heterogeneous in terms of social and economic conditions,<sup>9</sup> even in small areas (e.g. one city block), and can change over time.

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We therefore studied the degree of agreement between area-based SES measures and SES assessed at the individual level, rating the various area-based SES variables as to their proximity to the individual SES measure.

## Materials and Methods

### Study Population

This study was part of a larger study designed to investigate the indoor risk factors for airway hyper-responsiveness in Montreal school children. In order to represent a broad range of SES, all schools belonging to five school boards in central Montreal, Quebec, were ranked according to neighbourhood average house value<sup>14</sup> and, within each school board, schools were randomly selected from the upper, middle and lower ranks. One class was selected from each of the 18 schools from each of grades one (ages 6 and 7), three (ages 8 and 9) and five (ages 10 and 11).

Comparison of selected and non-selected schools showed no difference with respect to neighbourhood poverty, income or educational attainment level.<sup>14</sup> For example, for schools selected and not selected in the upper stratum (>\$95,000 neighbourhood average house value), the respective proportions of subjects living in poverty (as defined by Statistics Canada) were 6.1% ( $n = 6$ ) versus 5.4% ( $n = 115$ ),  $p = 0.83$ ; in the middle stratum (\$70,000–\$95,000 average house value) the respective values were 12.2% ( $n = 6$ ) versus 12.2% ( $n = 124$ ),  $p = 0.98$ ; and in the lower stratum (<\$70,000 average house value), they were 45.1% ( $n = 6$ ) versus 35.9% ( $n = 52$ ),  $p = 0.21$ .

### Assessment of Socio-economic Status at the Individual Level

At the individual (family) level, one parent's most recent occupation was used to assess the SES of the child. A trained person interviewed both parents at home in order to obtain a detailed employment history: the name of the company, type of industry, department within a company, job title, short job description, and year job began and ended. This information was collected for current and all preceding jobs. Information on the most recent occupation of the parent was used to identify the corresponding codes of the Canadian Classification and Dictionary of Occupations.<sup>15</sup> The codes were then converted into SES scores for the child, based on income and educational level for each occupation from the tables developed by Blishen and colleagues.<sup>16</sup> The highest score from either parent was retained for analysis (*individual level SES index*).

The validity of self-reported employment history is well established.<sup>17</sup> The correlations between the SES score derived from the most recent and from the previous three jobs respectively were  $r = 0.86$ ,  $r = 0.84$  and  $r = 0.62$  for the mothers' jobs and  $r = 0.87$ ,  $r = 0.84$  and  $r = 0.81$  for the fathers' jobs. The correlation between the fathers' and mothers' current jobs was  $r = 0.89$ .

Other proxy SES measures obtained at the individual level were number of people per room in the home (crowding index), single-parent family status and maximal level of education attained by either parent.

### Assessment of Socio-economic Status at the Area Level

By this method, socio-economic status for the individual (family of the child in this case) is inferred from the place of residence. In Canada, information on demographic factors, housing, income, education, quality of housing and other household characteristics is summarized at the level of enumeration area by Statistics Canada. Enumeration areas (EAs) represent census geostatistical neighbourhoods that contain up to a maximum of 375 households with relatively homogeneous economic and social living conditions. Census tracts (CTs) represent the next level of geostatistical area, containing between 2,500 and 8,000 (average of 4,000) residents. The boundaries of these areas have been drawn along recognizable divisions between neighbourhoods to create units that are as homogeneous as possible in socio-economic terms.<sup>14</sup>

The street address and postal code of the child's usual place of residence together with the Statistics Canada Postal Code Conversion File<sup>18</sup> were used to identify the enumeration area and census tract. The *Canada Postal Code Directory*<sup>19</sup> in hard copy was used to verify postal codes when the correct spelling of a street was in doubt. The validity of the Statistics Canada Postal Code Conversion file has been indirectly evaluated. The SES rankings of small geographic areas obtained using this conversion file have been found to accurately predict numerous health outcomes.<sup>20</sup>

The *1986 Census Dictionary*<sup>21</sup> and the code books of the 1986 census tape files prepared by Statistics Canada were used to select variables that were thought to reflect a neighbourhood's SES. Variables used in our analysis for both CTs and EAs were selected from the literature<sup>22–28</sup> on the basis of their frequency of use as social inequality indicators for small areas and were defined as follows.

*Net educational level*: the proportion of people aged 15 and over without a high school certificate or diploma subtracted from the proportion of people aged 15 and over with a university degree or post-secondary diploma for each small area (This variable is believed to be the most sensitive indicator of educational attainment.<sup>16</sup>)

*Proportion university educated*: the proportion of people aged 15 and over with a university degree or post-secondary diploma

*Median income*: median income of census families

*Income adequacy*: median income divided by family size of census families

*Average house value*: average house value of occupied private dwellings

*Proportion unemployed:* unemployed people aged 15 and over as a percentage of people aged 15 and over who were in the labour force

*Proportion of owned dwellings:* total owner-occupied private dwellings as a percentage of total occupied private dwellings

*Proportion of male parents:* the number of census families with a male parent as a percentage of total census families

*Proportion of female parents:* the number of census families with a female parent as a percentage of total census families

*Proportion of single parents:* the number of single-parent census families as a percentage of total census families

In addition to the above variables, the socio-economic status score for each occupation developed by Blishen and his colleagues<sup>16</sup> was weighted according to the proportion of people in each occupation category and summed, in order to get one SES score for each small area, *the neighbourhood SES index-I*; the z scores of net educational level, median income and proportion unemployed were

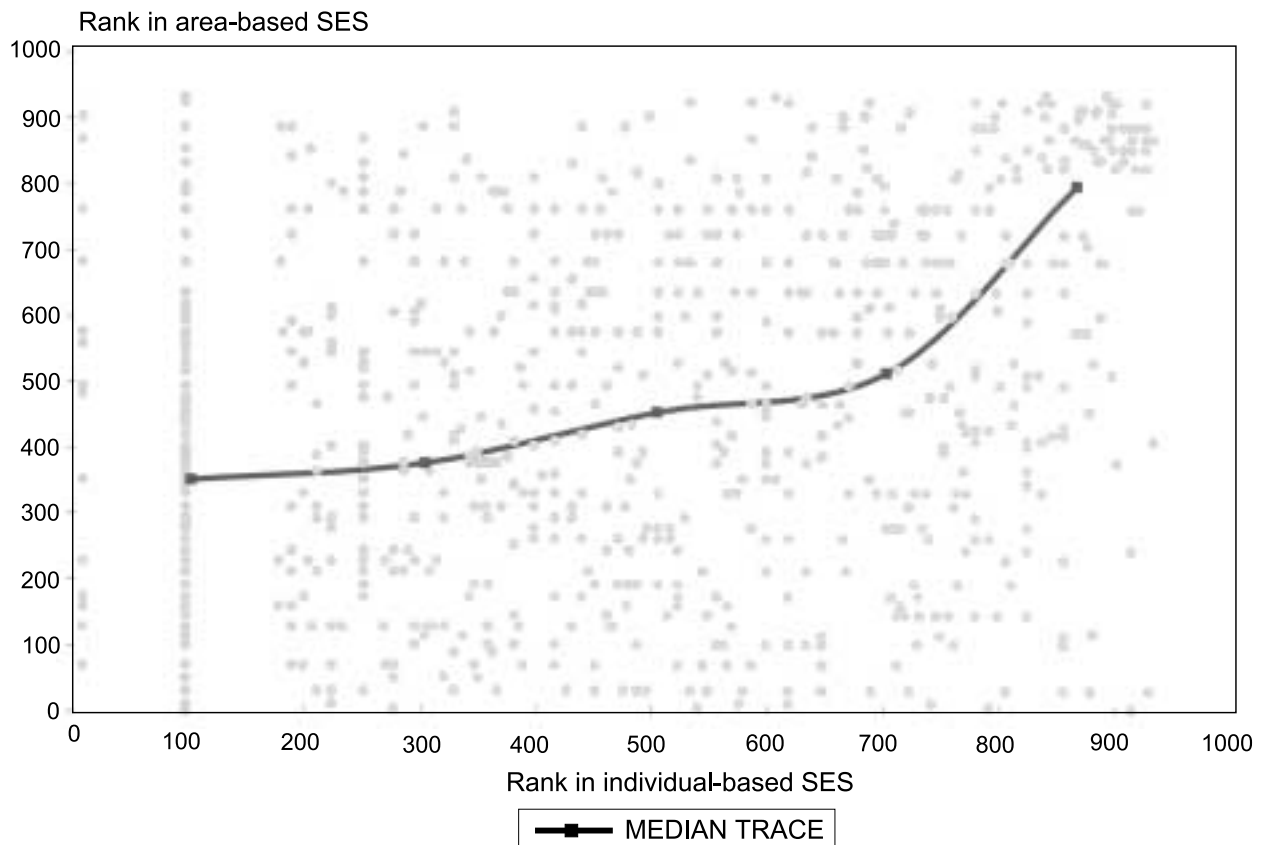
summed to create *the neighbourhood SES index-II*; and the z scores of net educational level, median income, average house value, proportion of owned dwellings and proportion of single parents were also summed to calculate the *neighbourhood SES index-III*.

These area-based SES variables were abstracted for each child in our sample at the EA level. To abstract the variables for the corresponding CTs, raw data were summed whenever possible before averages and proportions were calculated. If means and proportions of enumeration areas were used to derive variables at the CT level, appropriate weighting was used.

**Statistical Methods**

Agreement between the various area-based SES indices (at both CT and EA levels) and the individual level SES index was assessed in four ways. First, we used both the area-based and individual level SES scores to group the children into quintiles (quintile I having the most deprived and quintile V the least deprived), and we calculated the amount of agreement in classifying the child into the same or a close quintile by the two methods. Second, we ranked children according to the scores obtained from the two methods and used the ranks to plot the data and draw the median trace (Figure 1).

**FIGURE 1**  
**Neighbourhood SES index-I (at census tract level)**  
**versus the individual SES score ranks**



Third, we calculated Spearman's rank correlations of the various area-based SES indices with the individual-based SES indices. Finally, we used the ranks to calculate the intra-class correlation coefficient.<sup>29</sup>

Statistical analysis was carried out using SAS statistical software.<sup>30</sup>

## Results

From the 18 Montreal schools selected, 1,274 eligible children were identified, of whom 989 (77.6%) participated in the study; parental occupation could be coded into an SES score for 934 (94.4%) of these children. The postal codes for the addresses of 952 (96.3%) children could be linked to 117 corresponding census tract identifiers and 155 smaller enumeration area identifiers to determine area-based SES.

The 13 different area-based SES indices classified children as being within the same quintile as that determined by the individual level SES score 28.7% ( $\pm 2.8\%$ ) of the time. There was a discrepancy of one quintile in 35.3% ( $\pm 2.3\%$ ) of cases, two quintiles in 20.6% ( $\pm 3.6\%$ ), three quintiles in 11.3% ( $\pm 4.2\%$ ) and four quintiles in 4.1% ( $\pm 0.2\%$ ) of cases (Table 1). The degree of discrepancy was similar for area-based SES measures obtained at both the CT and EA level. Similarly, Spearman's rank correlations and the intra-class correlation coefficients between the area-based and individual level SES measures were always less than 0.40 (Table 2), suggesting little agreement. Figure 1 shows a scatter diagram with a median trace of the relation between occupation-derived, area-based SES measure (neighbourhood SES index-I) and the individual level SES. A wide variability around the median trace is evident.

Agreement of the various area-based SES indices with parental education, single-parent family status and crowding index obtained at an individual level was also poor and did not differ from that obtained for the individual level SES index (data not shown).

**TABLE 1**  
**Discrepancy between area-based measures of SES and SES assessed individually**

Area-based SES measures in quintiles	Level	Discrepancy by quintile (%)				
		None	One	Two	Three	Four
Net educational level	EA	30.7	32.0	21.8	11.3	4.3
	CT	30.4	33.9	20.8	10.8	4.1
Proportion university educated	EA	29.2	32.3	22.9	11.1	4.5
	CT	29.6	32.4	19.9	13.8	4.3
Median income	EA	30.5	37.4	19.4	8.5	4.3
	CT	34.2	34.9	17.7	8.9	4.3
Income adequacy	EA	29.7	36.3	21.4	9.0	3.6
	CT	29.5	39.6	18.2	9.0	3.8
Average house value	EA	25.1	33.3	24.7	13.0	3.9
	CT	25.9	33.6	23.4	12.7	4.3
Proportion unemployed	EA	29.8	34.7	20.6	10.7	4.3
	CT	29.0	39.9	18.6	9.2	3.3
Proportion of owned dwellings	EA	29.6	36.4	19.5	11.0	3.6
	CT	28.8	37.2	19.8	9.6	4.5
Proportion of male parents	EA	23.8	31.1	22.8	15.4	6.9
	CT	22.4	33.2	24.4	15.2	4.9
Proportion of female parents	EA	26.6	34.7	22.4	13.1	3.3
	CT	27.2	34.8	20.4	13.5	4.1
Proportion of single parents	EA	27.6	33.0	23.6	12.4	3.4
	CT	26.6	35.4	21.5	12.3	4.2
Neighbourhood SES index-I	EA	28.5	33.6	22.7	11.2	4.0
	CT	30.4	33.9	20.8	11.1	3.8
Neighbourhood SES index-II	EA	26.3	34.4	23.1	11.6	4.6
	CT	29.1	35.9	20.8	10.0	4.3
Neighbourhood SES index-III	EA	28.2	36.6	20.1	11.6	3.6
	CT	29.3	34.5	21.6	10.8	3.8

EA = Enumeration area  
CT = Census tract

## Discussion

We found poor agreement between the area-based and the individual level SES measures even when we used them to classify children into broad SES categories. The lack of agreement appeared across a wide distribution of both individual and neighbourhood indicators of SES, and a large number of small areas contained in various neighbourhoods were included. Furthermore, there were no important differences in terms of neighbourhood indicators of poverty between selected and non-selected schools, thus limiting selection bias.

Various methods and information have been used in forming area-based SES indices. In a British study, Campbell et al.<sup>22</sup> used unemployment rates in different areas. Wegner combined (with equal weighting) the z scores of mean years of education and mean income of subjects residing in a given census tract.<sup>23</sup> From examining determinants of mortality in Connecticut and Rhode Island, Stockwell<sup>24</sup> obtained the mean of the

**TABLE 2**  
**Spearman's rank correlation and intra-class correlation coefficients for the association of area-based SES measures with SES assessed individually**

Area-based SES measures	Census tract		Enumeration area	
	$r_s$	ICC	$r_s$	ICC
Net educational level	0.31	0.32	0.34	0.34
Proportion university educated	0.29	0.29	0.30	0.30
Median income	0.39	0.39	0.39	0.38
Income adequacy	0.39	0.39	0.37	0.37
Average house value	0.26	0.26	0.25	0.24
Proportion unemployed	0.38	0.38	0.31	0.31
Proportion of owned dwellings	0.34	0.34	0.34	0.35
Proportion of male parents	0.19	0.18	0.09	0.08
Proportion of female parents	0.30	0.30	0.30	0.29
Proportion of single parents	0.27	0.27	0.30	0.29
Neighbourhood SES index-I	0.31	0.31	0.31	0.31
Neighbourhood SES index-II	0.33	0.34	0.25	0.25
Neighbourhood SES index-III	0.33	0.33	0.33	0.32

ICC = Intra-class correlation coefficient  
 $r_s$  = Spearman's rank correlation

percentile scores for occupation, education and median income by census tract and subsequently modified this by adding the rental value of housing and the extent of overcrowding in dwelling units within each census tract. There is no standard way of constructing area-based indices, and the various methods used in the literature have not been compared with or rated on their relative proximity to information on SES that is specific to the individual.

In this study we compared and rated 13 different variables thought to be related to SES that could be derived from area-based information, and all correlated poorly with the individual SES measure. Furthermore, there were no substantial differences among them as to their proximity to SES assessed individually.

The strength of association between SES and disease outcome has been reported to vary according to the level of small area used in the analysis. For instance, in a study in which census tract was used as a small area of analysis, median rental values of residences were not found to be associated with endometrial cancer;<sup>7</sup> however, the same variable was associated with endometrial cancer when the unit of analysis was a residential block.<sup>8</sup>

In the present study, there was no substantial improvement when the smaller and potentially more homogeneous enumeration areas were used as opposed to the larger census tracts. This may have been the result of a close correspondence between enumeration areas and census tracts in our study sample, given that many more than 155 enumeration areas would be expected from 117 census tracts. One possible explanation for the small number of enumeration areas is that the school catchment areas were fairly small and may have included only a few enumeration areas from each census tract.

Individual level SES was used as a standard of reference with which area-based SES measures were compared. We used Blishen's SES index to measure individual level SES.<sup>16</sup> Parents were directly interviewed to obtain detailed employment histories, and this information was used to discriminate between the various occupations with similar job titles. The SES score assigned for each occupation has been developed after substantial research and is based on objective measures of educational level and income for each occupation. Blishen's SES index, developed for occupations in Canada, and its US counterpart (Duncan's SES index) are considered to be the most appropriate measures of ranking North American societies in terms of social and economic conditions. These composite measures are the most frequently used in social science research,<sup>31</sup> although they may not represent a true gold standard, given the complexities involved in the assessment of socio-economic status.

The poor agreement between the various area-based and individual SES measures is unlikely to have been due to intrinsic problems of the individual level Blishen ratings, because the area-based Blishen index (neighbourhood SES index-I) was found to have a similarly low agreement with the individual measures as the other area-based indices.

Persons of low and high SES tend to reside in certain areas within cities. Area-based measures of low SES appear to reflect a similar construct to that of low SES measured at the individual level, as shown in studies linking both levels of SES measures to various health indicators.<sup>4</sup> Area-based SES scores have been shown to be inversely related to all-cause mortality.<sup>24</sup> Among women, strong correlations have been found between standardized mortality ratios and area-based socio-economic variables.<sup>32</sup> Area-based SES variables have been linked to low birth weight, proportion of teenage mothers, non-immunized children and height as well as other potential markers of poor health.<sup>25,33</sup>

At issue in this type of analysis is the extent of measurement error that results when area-based SES measures are used. We expect the misclassification associated with area-based SES measures to be non-differential (i.e. the probabilities of exposure misclassification are the same in all groups being compared and unrelated to disease status). The effect of unreliable measurements, therefore, is to attenuate

exposure–outcome correlation or regression coefficients.<sup>29</sup> One consequence of attenuation is that a sample estimate of the observable correlation may fail to reach statistical significance, whereas a sample estimate of the correlation using more precise scores might be significant. The use of area-based SES measures may therefore involve use of larger sample sizes and incur additional costs.

A recent report from the US used a national sample to examine the use of census-based aggregate variables as a proxy for SES, concluding that associations of health outcomes with aggregate SES measures were substantially weaker than with micro-level measures.<sup>13</sup> From the intra-class correlation coefficients presented in Table 2, one can calculate a correction factor for the attenuated correlations.<sup>29</sup>

We used the 1986 Canadian census data to construct the area-based SES measures, whereas we obtained parental occupation for the period from April 1990 to November 1992. This time difference may have contributed to the lack of correlation between the individual and area-based measures of SES. Census data are collected only every 5 or 10 years in most countries, so that similar time differences are a regular feature of using area-based measures of SES. Geronimus and Bound<sup>13</sup> reported that the time lag between the primary data set being analyzed and collection of the census data makes little difference to area-based SES measures in predicting health outcomes.

In conclusion, we observed a substantial discrepancy between area-based SES measures and SES assessed on the basis of individually obtained information. Caution should therefore be used in designing or interpreting the results of studies in which area-based SES measures are used to test hypotheses or control for confounding.

## Acknowledgements

The study was approved by the Ethics Committee of the Department of Epidemiology and Biostatistics, McGill University, and was supported financially by the Medical Research Council of Canada and the Respiratory Health Network of Centres of Excellence (Canada).

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# *An Assessment of the Validity of a Computer System for Probabilistic Record Linkage of Birth and Infant Death Records in Canada*

*Martha Fair, Margaret Cyr, Alexander C Allen, Shi Wu Wen, Grace Guyon and Ralph C MacDonald, for the Fetal and Infant Health Study Group<sup>a</sup>*

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## **Abstract**

*Studies on the validity of probabilistic record linkage are sparse. We performed a probabilistic linkage to link the 1984–1994 birth records (obtained from the Canadian Birth Data Base) with 1984–1995 infant death records (from the Canadian Mortality Data Base) in Canada. We extracted the linked birth–death records for Nova Scotia and Alberta (from January 1990 to December 1991) obtained from Statistics Canada’s vital registration data and compared them with corresponding records from provincial data (primarily hospital records). The results showed that over 99% of infant deaths (153/155) in the Nova Scotia provincial data were successfully located in the linked Statistics Canada file; the corresponding figure for Alberta neonatal deaths was also 99% (365/367). The distributions of gestational age and birth weight in matched cases demonstrated high agreement between the two data sources. We conclude that the computer system for probabilistic linkage developed by Statistics Canada using the available personal identifying variables in the Canadian Birth Data Base and the Canadian Mortality Data Base is valid.*

**Key words:** *births; deaths; epidemiologic methods; infant; medical record linkage; validity*

## **Introduction**

Existing databases such as the Canadian Birth Data Base (CBDB)<sup>1</sup> and the Canadian Mortality Data Base (CMDB)<sup>2</sup> are attractive to health and health care analysts because they permit detailed studies of large populations. However, a single database may lack information that is crucial to the analysis. For example, information on birth weight and gestational age is usually recorded on birth registrations, whereas information on infant mortality is recorded on death registrations. Thus, an analysis of birth weight-specific or gestational age-specific infant mortality is impossible using separately registered data.

In recent years, developments in computerized record linkage methodology have made it possible to bring such

databases together.<sup>3–6</sup> To facilitate the surveillance of fetal and infant health, the Canadian Perinatal Surveillance System (CPSS) funded a record linkage of the Canadian Birth Data Base for 1985–1994 with infant deaths from the Canadian Mortality Data Base for 1985–1995 at Statistics Canada. A probabilistic linkage (or maximum likelihood linkage) was performed of infant death records with corresponding birth records using the Generalized Record Linkage System developed by Statistics Canada<sup>6,7</sup> and a calculated statistical probability based on relevant identifying variables (e.g. name, date of birth).

To assess the validity of this record linkage procedure, the records located in the Statistics Canada

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linked file were compared with information on the corresponding births and deaths collected independently by the provincial perinatal surveillance programs in Nova Scotia and Alberta. A full account of this validation study has been published by Statistics Canada as a technical report.<sup>8</sup> Studies on the validity of probabilistic linkage are sparse in the published literature, despite widespread use of this methodology in public health surveillance and epidemiologic research activities. We felt it important to disseminate the main results of this validation study to a broad audience through a peer-reviewed publication.

## Methods

### *The Linked Statistics Canada Birth and Death Files*

Statistics Canada's vital registration data are primarily collected through parental reporting at registration. The registrars of the 10 provinces and 2 territories collect data on live births, fetal deaths and other deaths. Paper and electronic (if available) copies of the registration documents are submitted to Statistics Canada under agreements between federal and provincial governments. The data are reformatted, edited, verified and stored in Statistics Canada's Integrated Vital Statistics files.

Statistics Canada's files were preprocessed into a format suitable for record linkage. A phonetic code from the New York State Individual and Intelligence System<sup>9</sup> was generated to encode the surname values so that, during the linkage process, records could be compared that had similar sounding surnames in order to check for misspelling or key entry errors. Data items from other sources, such as postal codes, were added, and alternative records were created using other surname fields (e.g. parental surnames). The 1990–1991 live birth events recorded in the CBDB were linked to the 1990–1992 deaths recorded in the CMDDB. A probabilistic record linkage was performed using the Generalized Record Linkage System,<sup>6,7</sup> which compares fields common to the two files, assigns weights to the resulting links and calculates a total weight. A weight of less than -90 would be automatically rejected, and a weight greater than +300 would be automatically accepted as a match. Manual resolution was carried out to confirm all linked records with a total weight ranging from -90 to 300, and to confirm all links to multiple births. Updates were made to the computer decisions where necessary, to create the linked Statistics Canada birth–infant death file.

Two subsets of the linked birth–death file were extracted for the validation comparison: (1) all 1990–1991 live birth–death linkages for which the province of birth was Nova Scotia and the age at death was 0–364 days (158 infant deaths); and (2) all 1990–1991 live birth–death linkages for which the province of birth and death was Alberta and the age at death was 0–< 28 days (371 neonatal deaths). These two provinces were chosen because they were the only ones with a perinatal data system that would allow an independent assessment of Statistic Canada's vital registration data.

### *The Nova Scotia and Alberta Provincial Data Files*

In contrast to Statistics Canada's vital registration data, the provincial perinatal data were obtained primarily from hospital discharge records.

The Reproductive Care Program of Nova Scotia supports the Nova Scotia Atlee Perinatal Database, which collects data on obstetric and neonatal events from hospital records in the province, including information on birth weight and gestational age.<sup>10</sup> To ensure that all cases are received by the Reproductive Care Program, these records are matched with Nova Scotia's vital statistics. Birth and death registration numbers are entered in the database. Records of infant deaths occurring after discharge from hospital are captured from Nova Scotia's vital statistics. Nova Scotia supplied the data for this validation study for births that took place only in Nova Scotia: babies born out of province and transferred to Nova Scotia were not included, nor were babies born out of province to Nova Scotia residents. The Nova Scotia file contains data for infant deaths occurring from 0 to 364 days after birth and includes birth weight and gestational age.

The Alberta Medical Association's Committee on Reproductive Care obtains mortality data from Alberta's hospital records for case review of fetal, neonatal and maternal deaths. Data are also collected from hospital birth records, including delivery, prenatal and newborn records as well as autopsy reports. Patient records are verified with Alberta's vital statistics (no information is extracted) to ensure that all cases have been received.<sup>11</sup> The cases reviewed were those for which the province of birth and death was Alberta: babies born out of province and transferred to Alberta were not included, nor were babies born out of province to Alberta residents. The Alberta file contains data for neonatal deaths occurring less than 28 days after birth and includes birth weight and gestational age.

In order for the records of deaths to be matched, each province was asked to provide Statistics Canada with a special file containing all infant (Nova Scotia) and neonatal (Alberta) deaths in 1990–1991.

### *Assessment Technique*

The Nova Scotia and Alberta files were processed at Statistics Canada to facilitate the match to the Statistics Canada files. Name fields were standardized, geographic fields were recoded and infant (neonatal) death records were grouped. Agreement (matching rate) between provincial records and Statistics Canada's records was used as the indicator of validity.

For data from Nova Scotia, the infant deaths on the provincial file were matched to the linked Statistics Canada file by the death registration and birth registration numbers supplied by the province. An exact match technique was employed using the SAS software package.<sup>12</sup> For data from Alberta, registration numbers were not available on the provincial fetal and neonatal death records. Therefore, they were matched using

common personal identifiers and processed together to maximize the number of individual matches.

Because there was no “type of event” field (i.e. live birth or stillbirth) on the Alberta file, this variable was imputed using “age at death” and “time of death” variables. When there were discrepancies in “type of event” between the Statistics Canada and Alberta files, the Alberta database administrator was contacted. There were 22 cases with such anomalies, 19 of which were corrected to agree with the Statistics Canada file; 3 of the 22 were not reconciled. In 2 of these cases, the records were coded as fetal death on the Alberta file and infant death on the linked Statistics Canada file. In the remaining case, the event was coded as neonatal death on the Alberta file and fetal death on the Statistics Canada file. For the 3 cases, Statistics Canada’s “type of event” code was used in the presentation of the results.

Three passes were executed to maximize the number of potential matches. The selected fields for matching in the first pass were sex, the first four bytes of the surname (equivalent to first four letters) and date of birth (year, month, day). The second pass used sex, the first four bytes of the surname field and birth weight. The third pass used sex and date of birth. All matches were manually verified.

Birth weight and gestational age in the two provincial files were compared with the Statistics Canada file if the records referred to the same individual.

## Results

### *Nova Scotia*

All but 2 (153/155, or 99%) of the infant deaths in the Nova Scotia file matched the corresponding Statistics Canada file. When gestational age was grouped by important analytic categories, agreement was found on 105 of 153 (70%) infant deaths (Table 1). Most of the disagreements were out by just plus or minus one category. When birth weight was grouped by important analytic categories, agreement was reached on 147 of 153 (96%) (Table 2).

### *Alberta*

All but 2 (365/367, or 99%) of the neonatal deaths in the Alberta file matched the corresponding Statistics Canada file. When gestational age was grouped by important analytic categories, there was agreement on 317 of 365 (87%) neonatal deaths (Table 3). When birth weight was grouped by important analytic categories, there was agreement on 354 of 365 (97%) (Table 4).

## Discussion

Probabilistic linkage is considered the preferable linkage method because the calculation of the probability can be refined in various respects to accommodate weights associated with identifier values and coding errors, and can thus maximize the available information. As a result, computer systems used for probabilistic

**TABLE 1**  
Comparison of gestational age on Statistics Canada’s records with gestational age on Nova Scotia’s records—infant deaths, for birth years 1990–1991

	Gestational age (weeks)	STATISTICS CANADA										Row total (%)
		20–21	22	23–24	25–26	27–28	29–31	32–33	34–36	37–41	≥42	
NOVA SCOTIA	20–21	1	3									4 (2.61)
	22		3		1							4 (2.61)
	23–24		4	12	1							17 (11.11)
	25–26			3	7	2						12 (7.84)
	27–28				2	8						10 (6.54)
	29–31			1	1	1	10		1			14 (9.15)
	32–33						1	3	2			6 (3.92)
	34–36				1			1	13	4		19 (12.42)
	37–41						1		3	43	4	51 (33.33)
	≥42									2	5	7 (4.58)
N/A	1		1	1				1	5		9 (5.88)	
	<b>Column total (%)</b>	<b>2 (1.31)</b>	<b>10 (6.54)</b>	<b>17 (11.11)</b>	<b>14 (9.15)</b>	<b>11 (7.19)</b>	<b>12 (7.84)</b>	<b>4 (2.61)</b>	<b>20 (13.07)</b>	<b>54 (35.29)</b>	<b>9 (5.88)</b>	<b>153 (100.00)</b>

**TABLE 2**  
**Comparison of birth weight on Statistics Canada's records with birth weight**  
**on Nova Scotia's records—infant deaths, for birth years 1990–1991**

	Birth weight (grams)	STATISTICS CANADA									Row total (%)	
		≤399	400–499	500–749	750–999	1000–1499	1500–2499	2500–4499	≥4500	N/A		
<b>N O V A S C O T I A</b>	≤399	4										4 (2.61)
	400–499		9						1			10 (6.54)
	500–749		2	20	1							23 (15.03)
	750–999			1	14							15 (9.80)
	1000–1499						11					11 (7.19)
	1500–2499							26				26 (16.99)
	2500–4499								60		1	61 (39.87)
	≥4500									3		3 (1.96)
<b>Column total (%)</b>	<b>4 (2.61)</b>	<b>11 (7.19)</b>	<b>21 (13.73)</b>	<b>15 (9.80)</b>	<b>11 (7.19)</b>	<b>26 (16.99)</b>	<b>61 (39.87)</b>	<b>3 (1.96)</b>	<b>1 (0.65)</b>	<b>153 (100.00)</b>		

**TABLE 3**  
**Comparison of gestational age on Statistics Canada's records with gestational age**  
**on Alberta's records—neonatal deaths, for birth years 1990–1991**

	Gestational age (weeks)	STATISTICS CANADA											Row total (%)
		≤20	20–21	22	23–24	25–26	27–28	29–31	32–33	34–36	37–41	≥42	
<b>A L B E R T A</b>	≤20		1										1 (0.27)
	20–21	3	27	3									33 (9.04)
	22		3	26	2								31 (8.49)
	23–24	1	2	4	55	4	1						67 (18.36)
	25–26			1	3	32	4				1		41 (11.23)
	27–28				1	2	27	2					32 (8.77)
	29–31						2	22					24 (6.58)
	32–33								12	2			14 (3.84)
	34–36									38	3		41 (11.23)
	37–41									2	72	1	75 (20.55)
	≥42											6	6 (1.64)
<b>Column total (%)</b>	<b>4 (1.10)</b>	<b>33 (9.04)</b>	<b>34 (9.32)</b>	<b>61 (16.71)</b>	<b>38 (10.41)</b>	<b>34 (9.32)</b>	<b>24 (6.58)</b>	<b>12 (3.29)</b>	<b>42 (11.51)</b>	<b>76 (20.82)</b>	<b>7 (1.92)</b>	<b>365 (100.00)</b>	

**TABLE 4**  
**Comparison of birth weight on Statistics Canada's records with birth weight**  
**on Alberta's records—neonatal deaths, for birth years 1990–1991**

	Birth weight (grams)	STATISTICS CANADA								Row total (%)	
		≤399	400–499	500–749	750–999	1000–1499	1500–2499	2500–4499	≥4500		N/A
<b>A L B E R T A</b>	≤399	29									29 (7.95)
	400–499	1	40								41 (11.23)
	500–749			81	1					1	83 (22.74)
	750–999				30						30 (8.22)
	1000–1499			1	1	45					47 (12.88)
	1500–2499						44				44 (12.05)
	2500–4499						1	84			85 (23.29)
	≥4500							4	1		5 (1.37)
	N/A				1						1 (0.27)
<b>Column total (%)</b>	<b>30 (8.22)</b>	<b>40 (10.96)</b>	<b>82 (22.47)</b>	<b>33 (9.04)</b>	<b>45 (12.33)</b>	<b>45 (12.33)</b>	<b>88 (24.11)</b>	<b>1 (0.27)</b>	<b>1 (0.27)</b>	<b>365 (100.00)</b>	

linkage, including the one developed by Statistics Canada, have become popular tools in large population-based studies.<sup>3–6</sup> However, before applying the methodology to different data sets, it is important to assess the validity of the linked records, that is, whether and to what extent the linked records are accurate.

The matching rate between provincial records and Statistics Canada's records is high: for the Nova Scotia file, 99% of the infant deaths were successfully located on the linked Statistics Canada file, and for Alberta neonatal deaths, the agreement was over 99%. The high agreement was demonstrated not only in the matching percentage of the study records but also in the agreement of birth weights obtained from these records. The agreement for gestational age, a variable that is more vulnerable to misclassification, was still quite satisfactory. The robustness of Statistics Canada's computer system is further documented by the consistently high agreement in data collected in this study from different jurisdictions through different data collection mechanisms and with different available personal identifying variables. Furthermore, a matching rate of 84–98% has been observed in a few earlier studies using similar methods.<sup>13–17</sup>

We acknowledge that there is no “gold standard” for the current study. Nova Scotia's and Alberta's provincial surveillance data may not necessarily be superior to Statistics Canada's registry data, and the reverse is also true. However, if we can assume that a high degree of agreement between records collected from two different

systems suggests a high degree of validity, then these results indicate that Statistic Canada's computer system for probabilistic linkage using the available personal identifying variables in the CBDB and the CMDDB is valid.

Record linkage also provides an opportunity to improve the data quality of participating databases. In this case, the linkage study located three infants born in Nova Scotia who had died in another province and who had not been identified on the Nova Scotia file. The linkage also located 22 events in Alberta (i.e. fetal or neonatal deaths) that had been incorrectly identified in the Alberta file.

This validation study examines the linkage results and analytic variables in only two provinces over a two-year period. Whether the results are applicable to other jurisdictions or other periods of time needs consideration. There may be variations in coding and recording practices over time and across jurisdictions. For example, some provinces have historically recorded birth weight in pounds and ounces whereas other provinces have used grams. Standard definitions and coding schemes are required in all jurisdictions in order to carry out a comprehensive comparison. Also noted within the Alberta file were inconsistencies between the type of death and the age of death. To improve record linkage, definitions should be followed precisely and the personal identifiers necessary for record linkage and grouping of analytic variables should be as complete as possible.

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# Infant Mortality by Gestational Age and Birth Weight in Canadian Provinces and Territories, 1990–1994 Births

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## Abstract

*We compared gestational age-specific and birth weight-specific infant mortality in the Canadian provinces (excluding Ontario) and territories using the linked birth and death records for 1990–1994 births. Compared with Quebec, early neonatal mortality rates were higher in Saskatchewan, Alberta and Newfoundland among extremely small and preterm infants and among infants with no information on gestational age and birth weight on their records. Post-neonatal mortality rates were higher in Prince Edward Island, Manitoba, Saskatchewan, Alberta, British Columbia and the Northwest Territories among preterm (and low birth weight) and term (and normal birth weight) infants. We suggest that differences in registration practices probably explain the substantial interprovincial variations in early neonatal mortality rates among extremely small and preterm infants, whereas differences in demographic profile and the quality of obstetric, neonatal and infant care probably explain interprovincial variations in infant mortality rates among less extremely small and preterm infants.*

**Key words:** birth weight; gestational age; infant mortality

## Introduction

In almost all countries throughout the world, infant mortality has dropped markedly over the last century with improvements in sanitation, nutrition, infant feeding, and maternal and child health care,<sup>1</sup> although the decline has been slower in recent years.<sup>2</sup> Disparities in the risk of infant death remain, however, even in countries like Canada, where universal health care has been in place since 1970.<sup>3</sup> For example, according to Statistics Canada figures, infant mortality for the combined years of 1991–1995 was 5.63 per 1,000 live births in Quebec but 13.22 per 1,000 live births in the Northwest Territories.<sup>4,5</sup>

Why should such disparities remain in Canada despite the availability of universal health care for three decades? Analysis of infant mortality rates in Canadian provinces and territories by gestational age and birth weight groups

may provide some hints. Improvements in, and access to, high-risk obstetric and neonatal care have led not only to markedly increased survival among extremely preterm newborns but to changes in registration practices of extremely small, immature newborns as well. Thus, births that were previously registered as spontaneous abortions (if they were registered at all) are now being registered as births, and births that were previously registered as stillbirths are now being registered as live births.<sup>6–10</sup>

If there were substantial regional differences in registration practices, it should primarily affect the calculated infant mortality rates in groups with extremely low gestational age and birth weight, rather than other gestational age and birth weight groups. On the other hand, if substantial differences in infant mortality rates were observed in less extremely small or preterm infants,

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disparities in factors related to maternal health and maternal, neonatal and infant care should be considered. To examine such potential disparities, we analyzed gestational age-specific and birth weight-specific infant mortality rates among Canadian provinces and territories.

## Methods

We used the linked birth and death records in Canada for births occurring from 1990 to 1994. Data processing and linkage procedures have been described elsewhere.<sup>11</sup> In brief, information on live births and deaths in Canada is collected by the registrars of the 10 provinces and 2 territories. Paper and electronic copies of the registration documents are submitted to Statistics Canada. Live birth data are stored in the Canadian Birth Data Base, and death data are stored in the Canadian Mortality Data Base.

To allow analysis of the relation between birth characteristics and death outcomes, Statistics Canada created a linked Canadian birth–death file for 1985–1994 birth records and 1985–1995 death records through the Canadian Perinatal Surveillance System. This linkage was based on a probabilistic procedure, using the Generalized Record Linkage System.<sup>12,13</sup> The Generalized Record Linkage System compares common fields in the two files, assigns weights to the resulting links and calculates a total weight. A weight of less than -90 would be automatically rejected and a weight of greater than +300 would be automatically accepted as a match. Manual resolution is carried out to confirm all linked records with a total weight ranging from -90 to +300 and all links to multiple births.

To reduce potential bias caused by secular trends in mortality and its determinants, we restricted our analysis to infants born between 1990 and 1994. Ontario data were excluded because of concerns about data quality.<sup>14</sup> Newfoundland data were restricted to births between 1991 and 1994, because data from this province were not available to Statistics Canada before 1991. In the provinces and territories studied, nine live births occurring between 1990 and 1994 with a gestational age of less than 22 weeks and a birth weight of less than 500 g appeared to have survived infancy. Because the probability of survival at these birth weights and gestational ages is negligible, the survival designation in these cases could have been due to missing death certificates. The vital status of such births was reclassified as death on the first day of life; this reclassification is identified in all analyses.

We calculated province-specific rates for early neonatal (0–6 days after birth), late neonatal (7–27 days after birth) and post-neonatal (28–365 days after birth) deaths, using all live births, survivors to the 7th day after birth and survivors to the 28th day after birth, respectively, as the denominators. Province-specific mortality rates were further calculated for the following gestational age and birth weight groups: <22 weeks, 22–23 weeks, 24–25 weeks, 26–27 weeks, 28–31 weeks, 32–33 weeks, 34–36 weeks, 37–41 weeks, 42 weeks and over, and not

available (missing) for gestational age; and <500 g, 500–749 g, 750–999 g, 1,000–1,249 g, 1,250–1,499 g, 1,500–1,999 g, 2,000–2,499 g, 2,500–3,999 g, 4,000 g and over, and not available for birth weight. Relative risks and 95% confidence intervals were estimated for each province. Quebec was used as the reference for the estimates because Quebec had both the largest population and the lowest infant mortality rate<sup>14</sup> among the provinces and territories studied.

To further explore the reasons for interprovincial variations in infant mortality, we also compared the distribution of important characteristics recorded on the birth certificate. We used mother's province of residence at delivery to calculate the province-specific rates and relative risks; nine births could not be assigned to a province or territory according to this variable and were excluded from these calculations.

Finally, to assess the potential impact of unlinked deaths and misclassification of birth weight and especially gestational age on the comparison of gestational age-specific and birth weight-specific mortality rates, we conducted supplementary analyses. In these, unlinked infant deaths were included in the calculation of overall early neonatal, late neonatal and post-neonatal mortality rates, and for those infants with a birth weight that deviated from the mean for a given gestational age by more than 5 standard deviations (based on the standard deviation for 1992–1994 live births), gestational age and birth weight were reclassified as “not available.”

## Results

A total of 1,230,938 births were registered by Statistics Canada for the nine provinces and two territories during the five-year study period. Among these, 1,223,895 were live births, 1,219,788 were live births surviving to the 7th day after birth and 1,218,928 were live births surviving to the 28th day after birth. Overall early neonatal, late neonatal and post-neonatal death rates were respectively 3.4, 0.7 and 2.3 per 1,000 live births. Of the 7,847 infant deaths, 199 could not be linked to birth records (i.e. the matching rate was 97.6%).

The majority of infants born before 22 weeks of gestation and a large proportion of those born before 24 weeks of gestation died soon after birth. Mortality rates were very high among infants born before 28 weeks and declined rapidly at higher gestational ages. Mortality rates reached their lowest level at term and increased slightly post-term. This “U”-shaped distribution in mortality rates was consistently observed in all provinces and territories studied, although some fluctuations did occur because of small samples in certain provinces and territories. Birth weight-specific mortality rates showed a similar pattern, with very high mortality in extremely low birth weight groups and a steep reduction at higher birth weights. However, unlike the situation for post-term infants, infants with large birth weight ( $\geq 4,000$  g) were not at increased risk of infant mortality as compared with

**TABLE 1**  
**Relative risk of early neonatal (0–6 days) death in Canadian provinces/territories<sup>a</sup>**  
**by gestational age group, 1990–1994 births**

Gestational age (weeks)	Relative risk (and 95% confidence interval)										Deaths per 1,000 live births
	NFLD	PEI	NS	NB	MAN	SASK	ALTA	BC	YUK	NWT	
<22	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	0.91 <sup>c</sup> (0.77–1.08)	1.01 <sup>c</sup> (0.96–1.07)	1.02 <sup>c</sup> (0.96–1.09)	NE (NE)	NE (NE)	944.8
22–23	0.78 (0.59–1.03)	NE (NE)	0.97 (0.84–1.11)	0.84 (0.66–1.06)	<b>1.11<sup>c</sup></b> (1.05–1.19)	0.91 (0.79–1.04)	0.98 (0.90–1.05)	1.05 (0.98–1.12)	NE (NE)	0.82 <sup>c</sup> (0.51–1.31)	870.8
24–25	0.93 (0.66–1.31)	0.46 <sup>c</sup> (0.13–1.56)	1.03 (0.81–1.30)	0.89 (0.66–1.21)	0.89 (0.69–1.16)	0.97 (0.77–1.23)	0.73 (0.61–0.88)	1.03 (0.88–1.21)	NE (NE)	0.34 <sup>c</sup> (0.06–2.06)	486.1
26–27	1.38 (0.78–2.44)	NE (NE)	0.75 (0.45–1.27)	0.98 (0.56–1.73)	1.15 (0.80–1.67)	<b>1.48</b> (1.02–2.15)	0.91 (0.66–1.24)	0.99 (0.74–1.32)	0.55 <sup>c</sup> (0.08–3.61)	<b>2.28</b> (1.18–4.39)	164.5
28–31	1.35 (0.81–2.26)	2.14 (0.99–4.63)	1.37 (0.93–2.03)	0.87 (0.50–1.51)	0.77 (0.50–1.18)	<b>1.53</b> (1.08–2.18)	1.12 (0.85–1.47)	1.09 (0.83–1.43)	NE (NE)	0.98 <sup>c</sup> (0.37–2.59)	52.9
32–33	1.70 (0.92–3.14)	1.86 <sup>c</sup> (0.47–7.29)	0.25 <sup>c</sup> (0.08–0.75)	1.48 (0.87–2.53)	0.55 (0.29–1.05)	1.11 (0.65–1.87)	0.96 (0.67–1.39)	0.84 (0.58–1.23)	NE (NE)	0.99 <sup>c</sup> (0.25–3.94)	25.6
34–36	1.19 (0.63–2.25)	1.49 <sup>c</sup> (0.55–3.99)	0.90 (0.57–1.44)	1.27 (0.80–2.02)	1.08 (0.92–1.53)	1.31 (0.90–1.93)	1.00 (0.76–1.32)	0.88 (0.66–1.18)	0.98 <sup>c</sup> (0.14–6.99)	0.88 <sup>c</sup> (0.28–2.73)	6.9
37–41	1.32 (0.89–1.97)	0.44 <sup>c</sup> (0.14–1.36)	1.06 (0.77–1.45)	1.22 (0.88–1.69)	1.18 (0.92–1.53)	1.02 (0.77–1.36)	0.97 (0.80–1.18)	0.95 (0.79–1.15)	1.12 <sup>c</sup> (0.28–4.51)	1.59 <sup>c</sup> (0.82–3.08)	0.8
42–47	1.71 (0.39–7.44)	NE (NE)	1.34 (0.59–3.03)	0.97 (0.28–3.33)	0.78 (0.31–2.00)	1.23 (0.48–3.15)	1.39 (0.66–2.93)	0.70 (0.32–1.50)	3.47 <sup>c</sup> (0.46–26.01)	NE (NE)	1.4
Not available	43.24 <sup>c</sup> (6.48–288.70)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	6.20 (2.39–16.04)	NE (NE)	NE (NE)	2.3
TOTAL <sup>d</sup>	<b>1.42</b> (1.18–1.71)	0.83 (0.55–1.24)	1.10 (0.95–1.27)	1.08 (0.91–1.27)	<b>1.15</b> (1.02–1.30)	<b>1.20</b> (1.06–1.36)	<b>1.11</b> (1.02–1.22)	1.05 (0.96–1.15)	1.35 (0.75–2.44)	1.25 (0.88–1.78)	3.1
TOTAL <sup>e</sup>	<b>1.38</b> (1.14–1.67)	0.79 (0.53–1.18)	1.06 (0.92–1.22)	1.03 (0.88–1.22)	<b>1.13</b> (1.00–1.27)	<b>1.14</b> (1.01–1.30)	1.06 (0.97–1.16)	1.06 (0.98–1.16)	1.28 (0.71–2.32)	1.38 (0.99–1.92)	3.3

Numbers in bold are statistically significant; NE = Not estimable because of cell(s) with value of 0; <sup>a</sup> Excluding Ontario; <sup>b</sup> Quebec is the reference for the relative risks.; <sup>c</sup> Small sample with cell(s) <5; <sup>d</sup> Not including unlinked cases; <sup>e</sup> Including unlinked cases

normal birth weight (2,500–3,999 g) infants (for detailed numbers and rates by province and territory see the perinatal health report from the Bureau of Reproductive and Child Health, Health Canada).

Compared with the province of Quebec, risks of early neonatal death, late neonatal death and post-neonatal death were substantially higher in most of the provinces and territories for most of the gestational age and birth weight groups (Tables 1–6), although we observed marked fluctuations due to small samples in several small provinces and territories.

Relatively large (relative risk >2.00) and statistically significant increases in risk were observed for early neonatal death at 26–27 weeks in the Northwest Territories; for late neonatal death at 24–25 weeks in Saskatchewan, and at 26–27 and 34–36 weeks in New

Brunswick; and for post-neonatal death at 24–25 weeks in Saskatchewan, at 32–41 weeks in the Northwest Territories and at 37–41 weeks in Prince Edward Island and Saskatchewan (Tables 1–3).

Relatively large and statistically significant increases in risk were also observed for early neonatal death at 1,250–1,499 g in Saskatchewan, at 1,500–1,999 g in Prince Edward Island and at ≥4,000 g in Newfoundland; for late neonatal death at <500 g in New Brunswick, Manitoba and Saskatchewan, at 500–749 g in Nova Scotia and Saskatchewan, at 750–999 g and 1,500–1,999 g in Newfoundland, and at 1,500–1,999 g in New Brunswick and Manitoba; and for post-neonatal death at <500 g in New Brunswick, at 750–999 g in Prince Edward Island, at all birth weights ≥1,250 g in the Northwest Territories, at 1,500–1,999 g, 2,500–3,999 g and 4,000 g and over in

**TABLE 2**  
**Relative risk of late neonatal (7–27 days) death in Canadian provinces/territories<sup>a</sup>**  
**by gestational age group, 1990–1994 births**

Gestational age (weeks)	Relative risk (and 95% confidence interval)										Deaths per 1,000 live births surviving at 7th day of life	
	NFLD	PEI	NS	NB	MAN	SASK	ALTA	BC	YUK	NWT		QUE <sup>b</sup>
<22	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	0.0
22–23	1.75 <sup>c</sup> (0.41–7.45)	NE (NE)	2.00 <sup>c</sup> (0.48–8.32)	3.00 <sup>c</sup> (0.92–9.75)	3.50 <sup>c</sup> (0.70–17.44)	2.15 <sup>c</sup> (0.68–6.81)	1.35 (0.43–4.17)	1.31 <sup>c</sup> (0.36–4.83)	NE (NE)	NE (NE)	NE (NE)	142.9
24–25	1.61 <sup>c</sup> (0.62–4.22)	NE (NE)	1.39 (0.61–3.16)	1.09 <sup>c</sup> (0.41–2.93)	0.79 <sup>c</sup> (0.29–2.16)	<b>2.51</b> <b>(1.39–4.53)</b>	1.26 (0.75–2.13)	0.93 (0.48–1.77)	NE (NE)	NE (NE)	NE (NE)	107.9
26–27	1.41 <sup>c</sup> (0.35–5.71)	2.39 <sup>c</sup> (0.36–15.99)	1.21 (0.47–3.09)	<b>2.52</b> <b>(1.07–5.90)</b>	1.35 (0.60–3.06)	1.48 (0.58–3.76)	1.16 (0.60–2.24)	1.01 (0.52–1.95)	NE (NE)	2.39 <sup>c</sup> (0.36–15.99)	NE (NE)	41.8
28–31	1.23 <sup>c</sup> (0.38–3.98)	NE (NE)	1.34 (0.56–3.18)	1.48 (0.58–3.77)	0.73 (0.29–1.88)	1.37 (0.61–3.09)	1.22 (0.69–2.17)	0.57 (0.27–1.28)	NE (NE)	NE (NE)	NE (NE)	12.5
32–33	1.75 <sup>c</sup> (0.41–7.58)	NE (NE)	NE (NE)	0.56 <sup>c</sup> (0.07–4.18)	0.61 <sup>c</sup> (0.14–2.63)	1.16 (0.34–3.96)	0.78 (0.31–2.00)	0.62 (0.23–1.68)	NE (NE)	NE (NE)	NE (NE)	4.7
34–36	1.78 <sup>c</sup> (0.55–5.78)	3.71 (0.89–15.41)	0.90 <sup>c</sup> (0.32–2.53)	<b>3.80</b> <b>(1.97–7.35)</b>	0.17 <sup>c</sup> (0.02–1.23)	1.27 (0.53–3.02)	1.54 (0.90–2.64)	0.93 (0.49–1.77)	NE (NE)	1.45 <sup>c</sup> (0.20–10.58)	NE (NE)	1.4
37–41	0.65 (0.29–1.47)	1.86 (0.82–4.20)	0.52 (0.28–0.99)	1.08 (0.66–1.78)	1.37 (0.96–1.95)	1.15 (0.77–1.70)	1.15 (0.88–1.50)	0.82 (0.62–1.10)	1.20 <sup>c</sup> (0.17–8.56)	1.50 <sup>c</sup> (0.56–4.06)	NE (NE)	0.4
42–47	NE (NE)	NE (NE)	0.68 <sup>c</sup> (0.14–3.28)	0.74 <sup>c</sup> (0.09–6.01)	NE (NE)	0.47 (0.06–3.82)	1.59 (0.53–4.71)	1.01 (0.35–2.88)	NE (NE)	NE (NE)	NE (NE)	0.6
Not available	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	<b>467.40<sup>c</sup></b> <b>(71.6–3052.1)</b>	NE (NE)	NE (NE)	NE (NE)	NE (NE)	0.5
TOTAL <sup>d</sup>	1.26 (0.82–1.95)	1.50 (0.77–2.92)	0.99 (0.44–2.23)	<b>1.62</b> <b>(1.20–2.18)</b>	1.16 (0.53–2.54)	<b>1.42</b> <b>(1.10–1.85)</b>	<b>1.30</b> <b>(1.08–1.57)</b>	0.84 (0.69–1.04)	0.59 (0.08–4.22)	1.17 (0.52–2.63)	NE (NE)	0.7
TOTAL <sup>e</sup>	1.24 (0.80–1.91)	1.47 (0.76–2.86)	0.89 (0.63–1.26)	<b>1.58</b> <b>(1.17–2.14)</b>	1.06 (0.80–1.40)	1.25 (0.97–1.63)	<b>1.29</b> <b>(1.07–1.55)</b>	0.86 (0.70–1.06)	0.58 (0.08–4.14)	1.53 (0.76–3.03)	NE (NE)	0.7

Numbers in bold are statistically significant.; NE = Not estimable because of cell(s) with value of 0; <sup>a</sup> Excluding Ontario; <sup>b</sup> Quebec is the reference for the relative risks.; <sup>c</sup> Small sample with cell(s) <5; <sup>d</sup> Not including unlinked cases; <sup>e</sup> Including unlinked cases

Saskatchewan, and at 4,000 g and over in Newfoundland (Tables 4–6).

Quebec had the lowest rate of teenage (<20 years) mothers, and the Northwest Territories had the highest rate (Table 7). Noticeable interprovincial variations were also observed in the proportions of mothers aged 35 and over and of primiparae. On the other hand, proportions of male sex and multi-fetal pregnancies were quite similar across the provinces and territories (Table 7).

Similar results were obtained after including unlinked infant deaths in the calculation of overall early neonatal, late neonatal and post-neonatal mortality (bottom row of Tables 1–6) and after reclassifying gestational age and

birth weight as “not available” for those infants with a birth weight that deviated from the mean for a given gestational age (week) by more than 5 standard deviations (data not shown).

## Discussion

An understanding of data quality and comparability is crucial for interpreting regional variations in infant mortality rates. Close scrutiny of Canada’s vital statistics data has identified errors in birth and death registries in the province of Ontario.<sup>14</sup> To ensure high data quality, we therefore excluded Ontario from our study.

**TABLE 3**  
**Relative risk of post-neonatal (28–365 days) death in Canadian provinces/territories<sup>a</sup>**  
**by gestational age group, 1990–1994 births**

Gestational age (weeks)	Relative risk (and 95% confidence interval)										Deaths per 1,000 live births surviving at 28th day of life	
	NFLD	PEI	NS	NB	MAN	SASK	ALTA	BC	YUK	NWT		QUE <sup>b</sup>
<22	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	0.0
22–23	1.00 <sup>c</sup> (0.14–7.10)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	0.67 <sup>c</sup> (0.09–4.99)	1.14 <sup>c</sup> (0.35–3.76)	0.46 (0.06–3.57)	NE (NE)	3.00 <sup>c</sup> (0.61–14.86)	166.7	
24–25	0.81 <sup>c</sup> (0.11–5.82)	NE (NE)	1.36 <sup>c</sup> (0.41–4.47)	2.05 <sup>c</sup> (0.72–5.81)	2.14 (0.87–5.26)	<b>2.63</b> ( <b>1.08–6.39</b> )	1.47 (0.72–3.00)	1.56 (0.74–3.33)	NE (NE)	NE (NE)	65.1	
26–27	1.84 <sup>c</sup> (0.05–2.36)	NE (NE)	1.67 (0.79–3.56)	1.16 <sup>c</sup> (0.36–3.67)	0.34 <sup>c</sup> (0.08–1.39)	0.78 <sup>c</sup> (0.24–2.49)	1.00 (0.53–1.90)	1.20 (0.67–2.13)	NE (NE)	2.18 <sup>c</sup> (0.33–14.34)	50.9	
28–31	0.33 <sup>c</sup> (0.05–2.36)	2.18 <sup>c</sup> (0.33–14.34)	0.18 <sup>c</sup> (0.02–1.29)	0.95 <sup>c</sup> (0.34–2.62)	1.28 (0.66–2.48)	1.41 (0.69–2.88)	<b>1.62</b> ( <b>1.01–2.60</b> )	1.31 (0.80–2.13)	NE (NE)	2.57 <sup>c</sup> (0.81–8.14)	16.0	
32–33	2.01 (0.80–5.09)	1.33 <sup>c</sup> (0.19–9.49)	1.23 (0.52–2.91)	0.51 <sup>c</sup> (0.12–2.10)	1.38 (0.69–2.78)	1.41 (0.66–3.03)	1.37 (0.81–2.31)	1.24 (0.73–2.10)	NE (NE)	<b>3.75<sup>c</sup></b> ( <b>1.18–11.92</b> )	10.4	
34–36	1.72 (0.84–3.53)	2.40 <sup>c</sup> (0.34–17.12)	0.98 (0.54–1.78)	1.38 (0.76–2.52)	<b>1.77</b> ( <b>1.17–2.68</b> )	<b>1.69</b> ( <b>1.06–2.68</b> )	<b>1.86</b> ( <b>1.37–2.52</b> )	<b>1.48</b> ( <b>1.06–2.06</b> )	NE (NE)	<b>4.73</b> ( <b>2.40–9.33</b> )	3.9	
37–41	1.23 (0.90–1.69)	<b>3.38</b> ( <b>1.38–8.26</b> )	1.14 (0.90–1.43)	1.14 (0.88–1.46)	<b>1.47</b> ( <b>1.23–1.76</b> )	<b>2.09</b> ( <b>1.78–2.45</b> )	<b>1.53</b> ( <b>1.35–1.74</b> )	<b>1.34</b> ( <b>1.18–1.52</b> )	0.97 <sup>c</sup> (0.31–3.03)	<b>4.48</b> ( <b>3.30–6.08</b> )	1.4	
42–47	1.96 <sup>c</sup> (0.45–8.61)	1.17 (0.69–1.99)	1.02 (0.39–2.66)	1.11 <sup>c</sup> (0.32–3.86)	1.34 (0.58–3.10)	1.64 (0.66–4.07)	0.92 (0.37–2.29)	1.44 (0.73–2.86)	3.97 <sup>c</sup> (0.52–30.07)	NE (NE)	1.2	
Not available	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	1.42 (0.19–10.46)	NE (NE)	NE (NE)	2.1	
TOTAL <sup>d</sup>	<b>1.33</b> ( <b>1.03–1.71</b> )	1.35 (0.88–2.06)	1.10 (0.91–1.34)	1.14 (0.92–1.41)	<b>1.46</b> ( <b>1.26–1.70</b> )	<b>1.90</b> ( <b>1.65–2.19</b> )	<b>1.54</b> ( <b>1.39–1.72</b> )	<b>1.33</b> ( <b>1.19–1.48</b> )	0.87 (0.33–2.32)	<b>4.36</b> ( <b>3.37–5.65</b> )	1.8	
TOTAL <sup>e</sup>	<b>1.37</b> ( <b>1.07–1.76</b> )	1.31 (0.86–2.01)	1.09 (0.90–1.33)	1.12 (0.91–1.38)	<b>1.42</b> ( <b>1.23–1.65</b> )	<b>1.89</b> ( <b>1.64–2.17</b> )	<b>1.51</b> ( <b>1.36–1.68</b> )	<b>1.31</b> ( <b>1.18–1.46</b> )	0.85 (0.32–2.26)	<b>4.58</b> ( <b>3.57–5.87</b> )	1.8	

Numbers in bold are statistically significant.; NE = Not estimable because of cell(s) with value of 0; <sup>a</sup> Excluding Ontario; <sup>b</sup> Quebec is the reference for the relative risks.; <sup>c</sup> Small sample with cell(s) <5; <sup>d</sup> Not including unlinked cases; <sup>e</sup> Including unlinked cases

The Generalized Record Linkage System used by Statistics Canada for the birth and death record linkage is a well-established system.<sup>11–13</sup> The matching rate was more than 97% for the provinces and territories studied, and the calculated overall mortality rates were similar when unlinked infant death cases were included. The quality of the linked birth and death records has been assessed by comparing the agreements for variables collected by two independent systems run in parallel in the provinces of Nova Scotia and Alberta.<sup>11</sup> This assessment demonstrated close agreement not only in the survival status of the linked records, but in gestational age and birth weight information as well.

Misclassification of birth weight and especially gestational age can occur in birth registry data,<sup>15</sup> which may affect comparisons of gestational age-specific and birth weight-specific mortality rates. However, results obtained after reclassifying gestational age and birth weight as not available for those infants with a birth weight for gestational age that deviated from the mean by more than 5 standard deviations did not differ from the original results. Misclassification appears to have had no major impact on our overall results.

Because of the profound effect on infant mortality of low birth weight, in general, and of extremely preterm birth, in particular,<sup>16–20</sup> differences in registration of

**TABLE 4**  
**Relative risk of early neonatal (0–6 days) death in Canadian provinces/territories<sup>a</sup>**  
**by birth weight group, 1990–1994 births**

Birth weight (grams)	Relative risk (and 95% confidence interval)										Deaths per 1,000 live births
	NFLD	PEI	NS	NB	MAN	SASK	ALTA	BC	YUK	NWT	
<500	0.94 (0.76–1.17)	NE (NE)	1.09 (0.66–10.20)	0.91 (0.75–1.12)	0.95 (0.85–1.06)	<b>1.12</b> ( <b>1.03–1.20</b> )	<b>1.08</b> ( <b>1.02–1.15</b> )	<b>1.15<sup>c</sup></b> ( <b>1.09–1.22</b> )	NE (NE)	0.39 <sup>c</sup> (0.08–1.92)	860.0
500–749	0.92 (0.71–1.20)	1.24 (0.82–1.87)	0.90 (0.72–1.12)	0.84 (0.67–1.17)	0.98 (0.83–1.17)	1.04 (0.88–1.24)	0.86 (0.75–0.98)	1.08 (0.97–1.21)	1.06 <sup>c</sup> (0.52–2.19)	0.83 (0.48–1.43)	563.5
750–999	1.34 (0.84–2.14)	0.46 <sup>c</sup> (0.07–3.00)	0.74 (0.48–1.15)	1.08 (0.71–1.65)	0.74 (0.51–1.18)	0.91 (0.61–1.34)	0.84 (0.64–1.11)	0.91 (0.70–1.19)	NE (NE)	1.09 <sup>c</sup> (0.39–2.99)	197.5
1,000–1,249	0.54 <sup>c</sup> (0.18–1.67)	NE (NE)	1.00 (0.56–1.78)	0.96 (0.50–1.85)	1.16 (0.73–1.84)	1.26 (0.76–2.09)	1.01 (0.77–1.58)	<b>1.45</b> ( <b>1.06–1.99</b> )	1.49 <sup>c</sup> (0.24–9.42)	1.18 <sup>c</sup> (0.65–5.42)	83.9
1,250–1,499	1.45 (0.59–3.53)	1.16 <sup>c</sup> (0.17–8.00)	1.67 (0.89–3.14)	1.51 (0.73–3.11)	1.23 (0.68–2.23)	<b>2.01</b> ( <b>1.17–3.45</b> )	<b>1.65</b> ( <b>1.10–2.49</b> )	1.07 (0.68–1.70)	NE (NE)	0.74 <sup>c</sup> (0.11–5.18)	41.1
1,500–1,999	1.41 (0.75–2.66)	<b>3.90</b> ( <b>1.88–8.10</b> )	0.62 (0.33–1.19)	<b>1.90</b> ( <b>1.22–2.98</b> )	0.76 (0.45–1.30)	<b>1.66</b> ( <b>1.10–2.49</b> )	1.04 (0.76–1.46)	0.98 (0.70–1.36)	NE (NE)	1.21 <sup>c</sup> (0.39–3.76)	22.7
2,000–2,499	1.65 (0.87–3.15)	0.51 <sup>c</sup> (0.07–3.62)	0.98 (0.55–1.73)	0.98 (0.51–1.87)	1.04 (0.63–1.70)	1.53 (0.98–2.39)	1.05 (0.76–1.46)	1.30 (0.96–1.78)	NE (NE)	1.17 <sup>c</sup> (0.29–4.71)	6.3
2,500–3,999	1.29 (0.84–1.99)	0.86 (0.35–2.08)	1.23 (0.91–1.68)	1.36 (0.99–1.89)	<b>1.30</b> ( <b>1.01–1.68</b> )	1.14 (0.86–1.51)	1.03 (0.84–1.25)	0.91 (0.75–1.12)	1.76 <sup>c</sup> (0.57–5.48)	<b>1.95<sup>c</sup></b> ( <b>1.04–3.66</b> )	0.8
4,000–6,999	<b>3.56</b> ( <b>1.52–8.33</b> )	NE (NE)	0.73 (0.22–2.45)	1.23 (0.42–3.57)	1.56 (0.72–3.39)	1.50 (0.64–3.50)	1.75 (0.95–3.22)	1.37 (0.75–2.51)	NE (NE)	NE (NE)	0.5
Not available	<b>16.47<sup>c</sup></b> ( <b>6.87–38.45</b> )	3.86 <sup>c</sup> (0.57–26.15)	2.26 (0.72–7.04)	NE (NE)	NE (NE)	NE (NE)	<b>12.35<sup>c</sup></b> ( <b>2.10–72.49</b> )	<b>4.62</b> ( <b>2.98–7.15</b> )	NE (NE)	3.86 <sup>c</sup> (0.57–26.15)	16.2
TOTAL <sup>d</sup>	<b>1.42</b> ( <b>1.18–1.71</b> )	0.83 (0.55–1.24)	1.10 (0.95–1.27)	1.08 (0.92–1.27)	<b>1.15</b> ( <b>1.02–1.30</b> )	<b>1.20</b> ( <b>1.06–1.36</b> )	<b>1.11</b> ( <b>1.02–1.22</b> )	1.05 (0.96–1.15)	1.35 (0.75–2.44)	1.25 (0.88–1.78)	3.1
TOTAL <sup>e</sup>	<b>1.38</b> ( <b>1.14–1.67</b> )	0.79 (0.53–1.18)	1.06 (0.92–1.22)	1.03 (0.88–1.22)	<b>1.13</b> ( <b>1.00–1.27</b> )	<b>1.14</b> ( <b>1.01–1.30</b> )	1.06 (0.97–1.16)	1.06 (0.98–1.16)	1.28 (0.71–2.32)	1.38 (0.99–1.92)	3.3

Numbers in bold are statistically significant.; NE = Not estimable because of cell(s) with value of 0; <sup>a</sup> Excluding Ontario; <sup>b</sup> Quebec is the reference for the relative risks.; <sup>c</sup> Small sample with cell(s) <5; <sup>d</sup> Not including unlinked cases; <sup>e</sup> Including unlinked cases

extremely small and immature infants (i.e. <500 g) as live births can severely compromise the comparison of infant mortality.<sup>14,20</sup> Regional variations may also exist in the registration of spontaneous or therapeutic abortions as births.<sup>6–10</sup> The substantial interprovincial variations in fetal and early neonatal mortality rates in infants of extremely preterm (<22 weeks of gestation) or low birth weight (<500 g) infants observed in our data (Tables 1–6) may have been caused, at least in part, by such differences in registration practices among Canadian provinces and territories. A similar inference can probably be made for births with no available gestational age or birth weight, since it is reasonable to assume that gestational age and birth weight were less likely to be recorded when extreme immaturity rendered viability unlikely.

Interprovincial variations in such factors as maternal health risks (e.g. genitourinary tract infection, cigarette smoking and substance abuse), quality of and access to both obstetric care (e.g. timely access to cesarean section) and neonatal intensive care, and quality of infant care (e.g. infant feeding, sleep positioning and injury prevention) may have played an important role in the observed interprovincial differences in mortality rates among less extremely small and preterm infants.

The provinces and territories with substantially higher rates in post-neonatal mortality, such as Manitoba, Saskatchewan, Alberta and the Northwest Territories, have proportionally larger native populations. It is widely recognized that post-neonatal mortality is much higher among native populations.<sup>21,22</sup> However, it seems difficult to attribute all of the increased post-neonatal

**TABLE 5**  
**Relative risk of late neonatal (7–27 days) death in Canadian provinces/territories<sup>a</sup>**  
**by birth weight group, 1990–1994 births**

Birth weight (grams)	Relative risk (and 95% confidence interval)										Deaths per 1,000 live births surviving at 7th day of life
	NFLD	PEI	NS	NB	MAN	SASK	ALTA	BC	YUK	NWT	
<500	NE (NE)	NE (NE)	NE (NE)	<b>7.78<sup>c</sup></b> (2.29–26.37)	<b>7.78<sup>c</sup></b> (2.29–26.37)	<b>5.83<sup>c</sup></b> (1.01–33.85)	2.92 <sup>c</sup> (0.68–12.56)	NE (NE)	NE (NE)	NE (NE)	85.7
500–749	1.72 <sup>c</sup> (0.65–4.57)	NE (NE)	<b>2.13</b> (1.02–4.42)	1.67 (0.73–3.84)	1.67 (0.73–3.84)	<b>3.72</b> (2.12–6.53)	<b>1.80</b> (1.08–2.99)	1.27 (0.69–2.34)	NE (NE)	NE (NE)	89.6
750–999	<b>3.23</b> (1.31–7.98)	NE (NE)	0.91 (0.32–2.56)	0.72 <sup>c</sup> (0.17–2.98)	0.72 <sup>c</sup> (0.17–2.98)	1.83 (0.85–3.96)	1.35 (0.72–2.51)	1.20 (0.62–2.31)	NE (NE)	1.40 <sup>c</sup> (0.21–9.08)	39.7
1,000–1,249	0.74 <sup>c</sup> (0.10–5.40)	3.31 <sup>c</sup> (0.48–23.01)	0.71 (0.17–3.00)	1.35 <sup>c</sup> (0.41–4.47)	1.35 <sup>c</sup> (0.41–4.47)	1.37 <sup>c</sup> (0.48–3.96)	0.59 (0.22–1.57)	0.66 (0.27–1.64)	NE (NE)	NE (NE)	21.6
1,250–1,499	NE (NE)	3.97 <sup>c</sup> (0.55–28.60)	NE (NE)	2.62 <sup>c</sup> (0.88–7.78)	2.62 <sup>c</sup> (0.88–7.78)	0.89 <sup>c</sup> (0.21–3.87)	1.72 (0.79–3.71)	0.56 <sup>c</sup> (0.19–1.69)	NE (NE)	NE (NE)	12.6
1,500–1,999	<b>3.81<sup>c</sup></b> (1.29–11.26)	NE (NE)	0.83 <sup>c</sup> (0.19–3.59)	<b>3.56</b> (1.41–8.98)	<b>3.56</b> (1.41–8.98)	2.01 (0.75–5.44)	1.46 (0.68–3.10)	0.53 <sup>c</sup> (0.18–1.59)	NE (NE)	NE (NE)	3.5
2,000–2,499	1.10 <sup>c</sup> (0.27–4.57)	1.68 <sup>c</sup> (0.23–12.20)	0.75 <sup>c</sup> (0.23–2.43)	1.95 (0.82–4.63)	1.95 (0.82–4.63)	1.33 (0.56–3.16)	0.81 (0.42–1.55)	1.08 (0.59–1.98)	NE (NE)	NE (NE)	1.9
2,500–3,999	0.77 (0.34–1.75)	1.88 (0.77–4.59)	0.75 (0.42–1.32)	1.31 (0.80–2.64)	1.31 (0.80–2.14)	1.16 (0.76–1.76)	<b>1.32</b> (1.01–1.73)	0.89 (0.66–1.19)	NE (NE)	1.94 <sup>c</sup> (0.27–14.13)	0.4
4,000–6,999	NE (NE)	1.91 <sup>c</sup> (0.25–14.42)	NE (NE)	NE (NE)	NE (NE)	0.59 <sup>c</sup> (0.14–2.56)	0.76 (0.30–1.94)	0.57 (0.22–1.44)	<b>8.60<sup>c</sup></b> (1.14–64.68)	1.28 <sup>c</sup> (0.41–4.03)	0.3
Not available	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	138.86 <sup>c</sup> (21.80–884.70)	1.66 (0.21–13.48)	NE (NE)	2.73 <sup>c</sup> (0.36–20.55)	1.8
TOTAL <sup>d</sup>	<b>1.26</b> (0.82–1.95)	1.50 (0.77–2.92)	0.99 (0.44–2.23)	<b>1.62</b> (1.20–2.18)	1.16 (0.53–2.54)	<b>1.42</b> (1.10–1.85)	<b>1.30</b> (1.08–1.57)	0.84 (0.69–1.04)	0.59 (0.08–4.22)	1.17 (0.52–2.63)	0.7
TOTAL <sup>e</sup>	1.24 (0.80–1.91)	1.47 (0.76–2.86)	0.89 (0.63–1.26)	<b>1.58</b> (1.17–2.14)	1.06 (0.80–1.40)	1.25 (0.97–1.63)	<b>1.29</b> (1.07–1.55)	0.86 (0.70–1.06)	0.58 (0.08–4.14)	1.53 (0.76–3.03)	0.7

Numbers in bold are statistically significant; NE = Not estimable because of cell(s) with value of 0; <sup>a</sup> Excluding Ontario; <sup>b</sup> Quebec is the reference for the relative risks.; <sup>c</sup> Small sample with cell(s) <5; <sup>d</sup> Not including unlinked cases; <sup>e</sup> Including unlinked cases

mortality to this factor. We speculate that interprovincial differences in other aspects of infant health and health care may have also played a role. For example, the proportion of infants born to teenage mothers, a known risk factor for post-neonatal mortality,<sup>23,24</sup> is lowest in the province of Quebec (Table 7).

In summary, our analysis of linked birth and death records in Canada revealed substantial interprovincial variation both in early neonatal mortality rates for extremely small and preterm infants and in infant mortality rates for less extremely small and preterm infants. These findings emphasize that, when comparing infant mortality among regions, it is important to assess

the regional differences in registration practices; as well, there remain major gaps among Canadian provinces and territories in terms of infant health and health care, despite a universal health care system that has been in place for three decades.

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**TABLE 6**  
**Relative risk of post-neonatal (28–365 days) death in Canadian provinces/territories<sup>a</sup>**  
**by birth weight group, 1990–1994 births**

Birth weight (grams)	Relative risk (and 95% confidence interval)										Deaths per 1,000 live births surviving at 28th day of life
	NFLD	PEI	NS	NB	MAN	SASK	ALTA	BC	YUK	NWT	
<500	NE (NE)	NE (NE)	NE (NE)	<b>16.00<sup>c</sup></b> (1.49–172.08)	2.29 <sup>c</sup> (0.15–34.00)	NE (NE)	3.56 <sup>c</sup> (0.25–51.41)	NE (NE)	NE (NE)	NE (NE)	31.3
500–749	2.05 (0.88–4.80)	NE (NE)	1.33 (0.55–3.22)	1.06 <sup>c</sup> (0.40–2.85)	1.20 (0.53–2.75)	1.20 <sup>c</sup> (0.45–3.21)	<b>1.73</b> (1.06–2.82)	0.85 (0.44–1.65)	NE (NE)	2.58 <sup>c</sup> (0.76–8.78)	110.7
750–999	NE (NE)	<b>4.03<sup>c</sup></b> (1.11–14.62)	1.13 (0.48–2.65)	0.89 <sup>c</sup> (0.28–2.84)	0.43 <sup>c</sup> (0.13–1.39)	1.38 (0.62–3.07)	0.76 (0.38–1.53)	1.09 (0.59–2.01)	NE (NE)	NE (NE)	49.6
1,000–1,249	1.27 <sup>c</sup> (0.31–5.28)	NE (NE)	0.61 (0.15–2.57)	0.79 <sup>c</sup> (0.19–3.30)	0.87 <sup>c</sup> (0.30–2.48)	1.51 (0.58–3.89)	1.43 (0.74–2.75)	1.05 (0.52–2.14)	NE (NE)	2.47 <sup>c</sup> (0.35–17.17)	25.3
1,250–1,499	0.87 <sup>c</sup> (0.12–6.49)	NE (NE)	NE (NE)	1.18 <sup>c</sup> (0.28–5.05)	1.13 <sup>c</sup> (0.38–3.34)	1.57 <sup>c</sup> (0.53–4.61)	1.65 (0.80–3.47)	1.48 (0.71–3.08)	NE (NE)	<b>4.32<sup>c</sup></b> (1.04–17.92)	14.5
1,500–1,999	0.76 <sup>c</sup> (0.19–3.13)	3.16 <sup>c</sup> (0.78–12.88)	1.48 (0.72–3.02)	0.95 <sup>c</sup> (0.34–2.62)	1.60 (0.85–3.03)	<b>2.24</b> (1.23–4.07)	<b>1.73</b> (1.10–2.71)	<b>1.79</b> (1.15–2.81)	NE (NE)	<b>4.29<sup>c</sup></b> (1.57–11.74)	8.8
2,000–2,499	1.08 (0.48–2.45)	0.55 <sup>c</sup> (0.08–3.92)	1.06 (0.60–1.88)	0.75 (0.35–1.60)	<b>1.69</b> (1.11–2.57)	<b>1.74</b> (1.12–2.71)	<b>1.40</b> (1.03–1.91)	1.20 (0.86–1.68)	NE (NE)	<b>3.82</b> (1.69–8.61)	5.8
2,500–3,999	1.36 (0.98–1.88)	1.53 (0.91–2.55)	1.12 (0.88–1.43)	1.28 (0.99–1.66)	<b>1.55</b> (1.29–1.87)	<b>2.02</b> (1.70–2.41)	<b>1.56</b> (1.36–1.78)	<b>1.45</b> (1.27–1.66)	1.39 <sup>c</sup> (0.52–3.72)	<b>4.75</b> (3.46–6.52)	1.4
4,000–6,999	<b>2.18</b> (1.02–4.66)	1.49 <sup>c</sup> (0.36–6.17)	1.18 (0.57–2.42)	0.99 (0.42–2.33)	1.67 (0.96–2.91)	<b>2.87</b> (1.74–4.71)	<b>1.92</b> (1.24–2.98)	<b>1.45</b> (1.27–1.66)	NE (NE)	<b>5.33</b> (2.11–13.45)	0.9
Not available	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	NE (NE)	<b>57.00<sup>c</sup></b> (10.36–313.69)	1.25 (0.79–1.97)	NE (NE)	NE (NE)	2.8
TOTAL <sup>d</sup>	<b>1.33</b> (1.03–1.71)	1.35 (0.88–2.06)	1.10 (0.91–1.34)	1.14 (0.92–1.41)	<b>1.46</b> (1.26–1.70)	<b>1.90</b> (1.65–2.19)	<b>1.54</b> (1.39–1.72)	<b>1.33</b> (1.19–1.48)	0.87 (0.33–2.32)	4.36 (3.37–5.65)	1.8
TOTAL <sup>e</sup>	<b>1.37</b> (1.07–1.76)	1.31 (0.86–2.01)	1.09 (0.90–1.33)	1.12 (0.91–1.38)	<b>1.42</b> (1.23–1.65)	<b>1.89</b> (1.64–2.17)	<b>1.51</b> (1.36–1.68)	<b>1.31</b> (1.18–1.46)	0.85 (0.32–2.26)	4.58 (3.57–5.87)	1.8

Numbers in bold are statistically significant.; NE = Not estimable because of cell(s) with value of 0; <sup>a</sup> Excluding Ontario; <sup>b</sup> Quebec is the reference for the relative risks.; <sup>c</sup> Small sample with cell(s) <5; <sup>d</sup> Not including unlinked cases; <sup>e</sup> Including unlinked cases

**TABLE 7**  
**Comparison of birth characteristics in Canadian provinces/territories, 1990–1994 births**

Characteristic	NFLD	PEI	NS	NB	QUE	MAN	SASK	ALTA	BC	YUK	NWT
% mothers <20 years	10.72	8.52	8.54	9.76	4.39	10.16	11.26	7.81	5.69	8.35	16.48
% mothers >35 years	4.27	6.12	5.87	4.25	6.14	6.04	4.92	6.64	8.58	9.19	4.53
% male infants	51.45	51.14	51.23	51.17	51.38	51.22	51.49	51.32	51.35	51.84	52.03
% multiple births	2.46	2.26	2.24	2.11	2.15	2.12	2.08	2.20	2.10	2.26	2.14
% primiparae	45.26	38.22	44.49	45.29	44.33	40.90	36.09	39.70	43.66	42.19	32.70

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# Status Report

## Canadian Strategy for Cancer Control

Silvana Luciani and Neil J Berman

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### Abstract

*The Canadian Strategy for Cancer Control is a stakeholder-driven initiative, led by a partnership between the Canadian Cancer Society, National Cancer Institute of Canada, Canadian Association of Provincial Cancer Agencies and Health Canada. The planning process began in January 1999 and currently involves more than 130 health professionals and community representatives who are volunteering their time, experience and expertise. A crucial aspect of the strategy's successful implementation is early participation of the provincial/territorial ministries of health in the planning process. Working groups are addressing 11 areas of the cancer continuum: prevention, screening, diagnosis, treatment, supportive care/rehabilitation, palliative care, pediatric cancer, research, human resource planning, surveillance and informatics/technology. Two stakeholder conferences will engage all cancer stakeholders in helping develop recommendations and establishing priorities for cancer control in Canada.*

**Key words:** cancer control strategy; health care; health policy

The concept of a coordinated strategic approach to cancer control is not new<sup>1</sup> or unique to Canada.<sup>2</sup> What is new is the growing consensus that now may be the last opportunity to plan for the looming, demographically induced burden of cancer, before our health care system becomes inundated by the rising prevalence and incidence of cancer in Canada. The imperative to deal with the coming crisis is driven not only by the economic costs that will be imposed on our health care system but also by the significant impact of human suffering on individuals, families and communities. The challenge is being faced by all groups, individuals and organizations that make up the cancer control mosaic in Canada, and indeed no single organization or institution has the resources or jurisdiction to address the problem alone. In recognition of this axiom, the Canadian Cancer Society (CCS), the National Cancer Institute of Canada (NCIC), the Canadian Association of Provincial Cancer Agencies (CAPCA) and Health Canada (HC) are leading a participatory process to develop the Canadian Strategy for Cancer Control.

The following definition of cancer control was adapted from a definition developed by the Advisory Committee on Cancer Control, National Cancer Institute of Canada.<sup>3</sup>

### What Is Cancer Control?

Cancer control aims to prevent cancer, cure cancer, and increase survival and quality of life for those who develop cancer, by converting the knowledge gained through research, surveillance and outcome evaluation into *strategies and actions*.

### How Do We Control Cancer?

Conduct *research* relevant to the biology of cancer, the underlying causes of cancer and methods for preventing, detecting and treating cancer

Develop *consensus* on the significance and implications of the results of cancer research, surveillance and outcome evaluation

Implement *strategies* based on scientific evidence to prevent cancer and to reduce its impact

Conduct *surveillance* to monitor and evaluate progress in cancer control

Starting in January 1999, a steering committee with representatives from the four leading organizations prepared a work plan for the strategy development process. The objective of the two-year process is to

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create, with the support of all the stakeholders in cancer control in Canada, a coordinated strategy with common goals aimed at reducing and dealing effectively with the cancer burden.

Participation by provincial/territorial ministries of health at all stages of this initiative is paramount, since ultimately they will be the ones to set policies and program priorities for the implementation of most of the strategy recommendations. The complexity and diversity of the way the provincial/territorial ministries organize cancer care require multiple and mutually reinforcing methods to ensure appropriate participation in this process. To date, the federal/provincial/territorial advisory committees (Advisory Committee on Population Health [ACPH], Advisory Committee on Health Services, Advisory Committee on Human Health Resources and Advisory Committee on Health Information) have been invited to indicate how actively their jurisdictions wish to participate in the development of the strategy. Representatives from provincial/territorial ministries are participating in the main planning bodies (see next section).

The strategy will apply current knowledge on cancer causes, diagnosis, treatment, survival and quality-of-life issues to actions that will prevent, cure and manage cancer. The focus will be on the following activities.

Achieving consensus on goals and priorities that will reduce the premature mortality and morbidity caused by cancer, encouraging health-promoting behaviours, reducing exposure to cancer risk factors and improving the quality of life of those affected by cancer

Linking existing cancer strategies (such as the Canadian Breast Cancer Initiative, the Prostate Cancer Research Initiative and the Canadian Coalition on Cancer Surveillance) to a comprehensive framework that addresses current and emerging cancer issues

Denoting clear roles and responsibilities among the jurisdictions involved in cancer control

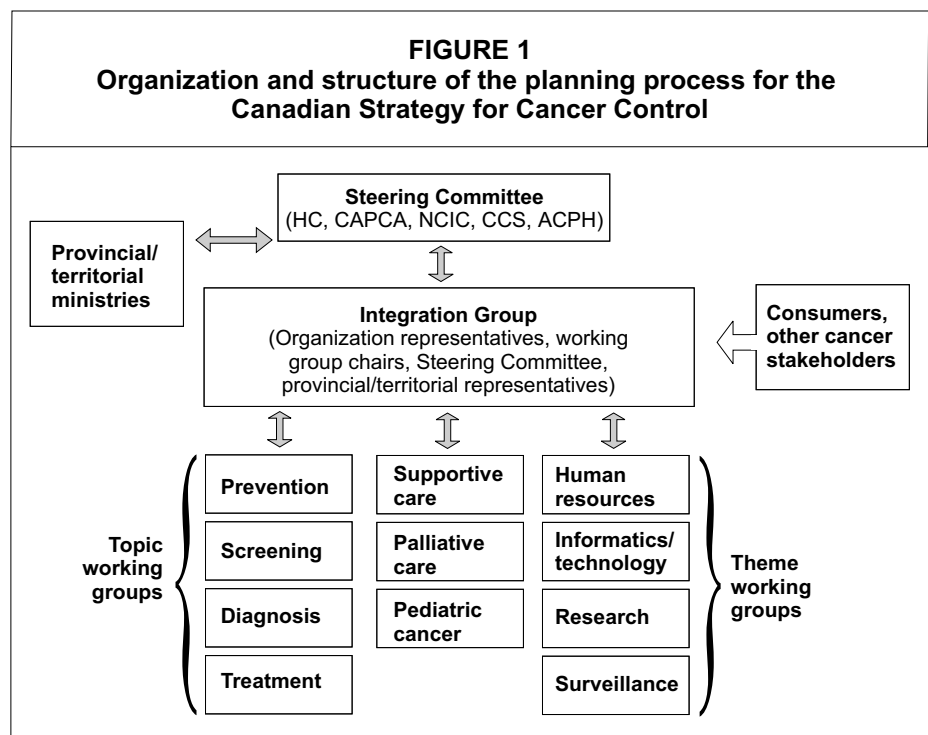
Creating enduring mechanisms for national cooperation and partnerships among various stakeholders

## Broad Support and Expert Input

The strategy planning process has generated tremendous support and momentum among the organizations and health professionals working in the field of cancer control. This commitment is reflected in the structure and organization of the initiative (see Figure 1) and the more than 130 professionals and community representatives engaged in this planning process.

Eleven topic and theme working groups of volunteer professionals and community representatives have been established to examine issues of priority and the evidence and opportunities for intervention, and to make recommendations for the subject area (see Table 1). Chairs have been appointed by the Steering Committee. The working groups' recommendations will be presented to an oversight committee, named the Integration Group. This group is coordinating the strategy's content by directing the working groups, reviewing their recommendations and promoting integration across topic and theme areas. It is composed of the chairs of each working group, representatives of national health organizations, community representatives and experts in cancer control (see Table 2). All stages of the strategy planning process are being led by the Steering Committee, which comprises senior executives of the four partner organizations. A cancer control secretariat at Health Canada has been established to coordinate and facilitate the planning process.

A broad range of representatives of cancer control stakeholders will be invited to attend two national conferences: one will be held at the midpoint of the



**TABLE 1**  
**Issues being examined by the topic and theme working groups of the Canadian Strategy for Cancer Control**

	Issues
<b>Topic working group (Chair)</b>	
<b>Prevention</b> (Ellen Murphy, Alberta Cancer Board)	Recommendations for a cancer prevention system that could be integrated into the formal care system
<b>Screening</b> (Richard Schabas, Cancer Care Ontario)	A conceptual framework, process for program guideline review and evaluation, organizational elements for programs/guidelines. Propose Canadian Cancer Research and Evaluation Network, National Cancer Screening Committee
<b>Diagnosis</b> (Eva Grunfeld, Ottawa Regional Cancer Centre)	Diagnostic assessment, delay, staging assessment, psychosocial outcomes, clinical outcomes, education, patient-physician communication, diagnostic assessment units
<b>Treatment</b> (Simon Sutcliffe, BC Cancer Agency)	System capacity and service delivery: radiation therapy, systemic therapy, surgical oncology; integrated case management; relation between conventional medicine and complementary and alternative medicine; clinical trials/research; clinical practice guidelines
<b>Supportive care</b> (Richard Doll, BC Cancer Agency)	Identifying needs and gaps in supportive care services, including emotional/cognitive, information, spiritual, physical and practical needs
<b>Palliative care</b> (Neil Hagen, University of Calgary)	Research, education, program delivery, cancer control
<b>Pediatric cancer</b> (Mark Bernstein, Ste-Justine Hospital)	Basic scientific infrastructure, human resources, delivery of care in large and small institutions, surveillance, supportive and palliative care
<b>Theme working group (Chair)</b>	
<b>Research</b> (Victor Ling, BC Cancer Research Centre)	Emphasis on research needs for service delivery, prevention, screening, supportive and palliative care
<b>Surveillance</b> (Roy West, University of Newfoundland)	Integration of the needs of the strategy with the activities of the Canadian Coalition on Cancer Surveillance
<b>Human resource planning</b> (Andrew Padmos, Cancer Care Nova Scotia)	National Cancer Work Force Strategy: national database on human resources supply and demand; Saskatchewan: workforce training programs, immigration, emigration; Ontario: database on cancer professionals; British Columbia: compensation and benefits
<b>Informatics and technology</b> (Kathryn Hannah, University of Calgary)	Information management model, public access to information, electronic patient records

**TABLE 2**  
**Members of the Integration Group**

<ul style="list-style-type: none"> <li>• Association of Canadian Medical Colleges</li> <li>• Canadian Association of Nurses in Oncology</li> <li>• Canadian Association of Psychosocial Oncology</li> <li>• Canadian Association of Radiation Oncology</li> <li>• Canadian Coalition on Cancer Surveillance</li> <li>• Canadian Oncology Society</li> <li>• Canadian Public Health Association</li> <li>• Chairs of working groups</li> <li>• College of Family Physicians of Canada</li> <li>• Community representatives</li> <li>• Consumers' Association of Canada</li> <li>• Provincial/territorial representation</li> <li>• Steering Committee</li> </ul>
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strategy's planning process to provide input and feedback on the preliminary recommendations from each working group, and the other will take place toward the end of the planning process to establish priorities for action. The participation of the broader cancer control community, such as site-specific cancer support groups and allied health professionals, is required to provide the basis of support on which a coordinated strategy can be built. Implementation of a coordinated strategy will necessarily require broad agreement on national strategic priorities. It is anticipated that such input will be obtained not only by means of the stakeholder conferences but also through participation in the partnerships and mechanisms required to implement the strategy.

### Opportunities

The successful creation of a national strategy with agreed-upon goals will create opportunities for a coordinated, collaborative effort on a major public health issue, sharing of responsibility across a number of organizations, specific interventions that would otherwise be impractical and structures with broad support that could address emerging issues in cancer control.

Specific opportunities that may be achievable within the context of a coordinated strategic framework could include a national mechanism for the evaluation and clarification of cancer screening programs and guidelines, a national mechanism for the monitoring and coordination of human resource supply and demand in cancer care and treatment, and establishment of research networks that target topics in cancer control deemed to be of national priority.

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# Status Report

## Canadian Coalition on Cancer Surveillance

Barbara Foster and Anna Maria Boscaino, for the CCOCS Management Committee

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### Background

In Canada, there are many separate systems collecting and storing cancer data. For the most part these systems work independently of one another and use varying methods of data collection and analysis. As a result, much of the existing surveillance information on cancer is not available in an integrated format. The Canadian Coalition on Cancer Surveillance (CCOCS) was created to lead the development of an integrated national cancer surveillance system. Once operational, this system will link existing provincial and national systems, in effect creating a “network of networks,” and it will provide information for cancer control planners, providers and policy-makers of today and tomorrow. Surveillance is an integral component of the cancer control continuum, and the CCOCS is working in tandem with the Canadian Strategy for Cancer Control initiative.

A five-year business plan for the CCOCS, developed in 1998, outlined the areas paramount to the development of a national cancer surveillance system. Seven working groups have addressed cancer information management gaps by consulting and building consensus with expert cancer stakeholders to develop standards and guidelines. Sub-working groups have evolved to work on the specific recommendations of their leader working groups.

Numerous national initiatives have generated new challenges and opportunities. These include the formalization of the Canadian Association of Provincial Cancer Agencies [see related Status Report in this issue], the Road Map Initiative (Statistics Canada and the Canadian Institute for Health Information), the National Health Surveillance InfoStructure (Health Canada) and the Canadian Strategy for Cancer Control (Health Canada, National Cancer Institute of Canada, Canadian Cancer Society and the Canadian Association of Provincial Cancer Agencies) [see related Status Report in this issue]. The CCOCS has been responsive to these changes. Revisions have been made to the strategic plan that adapt and redirect our strategies, but the vision and dedication

of all the key players remain strong. This status report presents the progress of the CCOCS to date, including its accomplishments and anticipated next steps.

### Partnerships

The CCOCS has cemented strong partnerships with a range of key cancer stakeholders, from non-governmental organizations and federal/provincial/territorial departments, to researchers and clinicians, professional societies and consumers. Organizations and individuals have contributed by providing representatives on one or more working groups, disseminating information, supplying expert advice or funding activities or projects recommended by the CCOCS.

### Leadership

The Coalition’s organizational structure consists of the Management Committee, the Advisory Committee and working groups. The Management Committee includes representatives of the organizations that have contributed funds towards this initiative. With the guidance of the Advisory Committee, the Management Committee approves projects and activities, sets priorities, liaises with other national organizations, seeks alternative funding sources and oversees the general direction and management of the CCOCS.

The Advisory Committee—the original planning group—includes the key funders, all working group and sub-working group leaders, other key cancer stakeholders and consumers. The Advisory Committee coordinates input from the working groups, accepts or rejects their recommendations/directions, recommends priorities, prepares cost estimates and considers input from similar national organizations for possible integration with the activities of the CCOCS. The working groups comprise representatives with the professional expertise necessary to determine the requirements and directions for the various components of a national cancer surveillance program.

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### Author References

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## Funding

The CCOCS Advisory Committee prepared an estimated five-year budget for the development of a national cancer surveillance system. Funding was secured from partners and other organizations to move forward on the first year's activities. The actual budget was less than one tenth of the desired amount. Nevertheless, with limited financial and human resources from key partners (Health Canada, Laboratory Centre for Disease Control [Christina Mills], the National Cancer Institute of Canada [Barbara Whyllie, Chair], the Canadian Association of Provincial Cancer Agencies [Bertha Paulse] and the Canadian Cancer Registry [Diane Robson]) and funding for specific projects from Statistics Canada and the Canadian Institute for Health Information, the CCOCS has adjusted some of its priorities and made steady progress toward reaching its desired concrete goals, although the time lines have been altered and the scale has been somewhat reduced. The following section briefly outlines the various activities now being pursued by the CCOCS.

## Current Activities

### **Legislative Framework Working Group**

#### **Deliverable goal**

*Compendium of surveillance system legislation affecting the collection, use and disclosure of cancer-specific health information with the required recommendations to develop model legislation concerning privacy, access and security*

The Legislative Framework Working Group, under the leadership of Eric Holowaty (Cancer Care Ontario), has contracted an academic-based group of lawyers to conduct an inventory and analysis of provincial, territorial and federal legislation affecting the collection, use and disclosure of health information in 13 jurisdictions. The resulting report will recommend suggested changes to current legislation and/or the creation of new model legislation. The report will be circulated to cancer stakeholders, including the Canadian Strategy for Cancer Control and those in other disease areas who are dealing with similar legislative issues.

### **Patient Management Working Group**

#### **Deliverable goals**

*Expanded set of core variables related to patient demographic information and treatment that is accepted by all jurisdictions*

*Confirmation of the feasibility of collecting these variables*

*Collection of the variables by all provincial and territorial cancer registries and by the national cancer registry*

*Collection of consistent and accurate stage information on all appropriate incident cancer cases, and development of enabling tools*

The Patient Management Working Group, under the direction of Bill Evans (Cancer Care Ontario), is moving forward through several activities within the following theme areas.

Quality and consistency of the core data set definitions (see Quality Management section)

Staging collection and completeness

Treatment data (radiotherapy: data availability and standards)

In the staging arena, the CCOCS is collaborating with key cancer stakeholders and, in particular, it holds a seat on the National Cancer Institute of Canada (NCIC) Staging Subcommittee. This committee advocates the use of tumour node metastasis (TNM) staging on a national basis for all newly diagnosed cancer patients. Statistics Canada and the NCIC are co-funding the Minimum Investigations Required to Stage Project, which will provide an educational resource for physicians to ensure consistency, accuracy and quality of staging information for the four most common cancers.

The Radiotherapy Sub-working Group, led by John Hay (British Columbia Cancer Agency), is surveying the 36 radiotherapy treatment facilities across Canada to establish a baseline of the information now being collected and the definitions used. The results of the survey will form the basis of the next phase of the project: the piloting of the collection of radiation treatment information in two or three provinces. Survey results are expected to be compiled by late spring 2000.

### **Quality Management Working Group**

#### **Deliverable goal**

*Implementation of a quality management program that ensures compliance with a generally accepted set of quality standards and promotes continuous improvement in the accuracy and utility of the data collected*

The CCOCS hosted the "Maximizing Our Potential" Case Ascertainment Workshop in Ottawa, May 12–13, 1999 (funded by Health Canada). The workshop participants developed recommendations for actions needed to establish a quality management program within the Canadian Cancer Registry. The CCOCS Management Committee was instrumental in bringing the recommendations forward and soliciting funding. To this end, a standards development project has been funded by the Road Map Initiative (Statistics Canada). It is hoped that this project will result in generally accepted quality standards and methods for case ascertainment for the provincial and territorial cancer registries. Statistics Canada has also agreed to devote dedicated human resources toward standards development, to develop

procedures for managing coding inconsistencies and to create benchmark indicators for the provincial and territorial cancer registries.

Implementation of the Patient Management Core Data will inevitably fall to the Canadian Council of Cancer Registries, which has agreed to form a task force to discuss strategies and next steps. The CCOCS Advisory Committee requested that the Data Definitions Working Group (Chair—Darlene Dale, Cancer Care Ontario) of the Canadian Council of Cancer Registries apply its expertise in the area of definitions and quality assurance for the refinement of the Patient Management Core Data Set. This group has accepted the challenge, and a February 2000 meeting was held to move this forward.

### **Population/Public Health Working Group**

#### **Deliverable goal**

*Acceptance by provincial, territorial and federal organizations of the need for a core data set of cancer risk factors and screening behaviours, followed by development of such a data set*

The Population/Public Health Working Group, led by Howard Morrison (Health Canada, Laboratory Centre for Disease Control) and Odette Laplante (Quebec Ministry of Health), has created a resource of standardized questions in the areas of screening and risk factors, categorized as knowledge, attitudes and behaviours. Within the screening component, the following sites will be addressed: breast, cervical, colorectal, prostate and emerging (genetics). Smoking, nutrition, physical activity and environmental/occupational health will be dealt with in the risk factors area.

This working group has also developed a link with Statistics Canada and, specifically, the Canadian Community Health Survey (CCHS), a new initiative that will sample the Canadian public on a wide variety of health-related and demographic questions (sample size 130,000). The CCHS is receptive to input from the Population/Public Health Working Group on subject areas such as nutrition and smoking. A meeting of the working group is planned for spring 2000 to finalize questions, discuss dissemination strategies and brainstorm on how best to interact with other disease groups whose risk factors are similar, e.g. cardiovascular disease.

### **Costs Working Group**

The Costs Working Group is led by Hugh Walker (Queen's University) with Brian Schmidt (British Columbia Cancer Agency) as leader of the Management Information System (MIS) Sub-working Group. The MIS Sub-working Group met on January 25–26, 1999, to augment and improve the MIS Guidelines Chart of Functional Accounts for use within provincial cancer agencies. These guidelines are administered by the Canadian Institute for Health Information. Once approved by the Institute and the MIS coordinators, it is anticipated that the cancer-specific MIS guidelines will be operational in the provincial cancer agencies in the year 2001.

A future meeting of provincial chief finance officers from each provincial cancer agency will address opportunities and problems after implementation of the guidelines. One of the activities of the meeting will be to discuss the creation, use and dissemination of a report based on the application of the guidelines, which will provide interprovincial comparisons and national analyses from a costing perspective. The Canadian Association of Provincial Cancer Agencies will be a major target audience for the report.

### **Cancer Progress Report Working Group (formerly Knowledge Synthesis)**

#### **Deliverable goal**

*Creation and implementation of a process for regular production and publication of data to monitor and report on cancer progress*

The CCOCS hosted the Cancer Progress Report Working Group Workshop on June 16, 1999, in Toronto, led by John McLaughlin (Mount Sinai Hospital). The workshop resulted in a draft report that suggested the following themes with appropriate indicators to be included in a national cancer progress report: prevention, detection, treatment and palliation. The Cancer Bureau in Health Canada's Laboratory Centre for Disease Control has agreed to take the lead in implementing the cancer progress report; the CCOCS secretariat will assist with coordination and act as liaison with appropriate partners.

### **Collaboration**

Information management and technological needs for cancer surveillance will be addressed by the Canadian Strategy for Cancer Control's informatics theme working group to ensure continuity and prevent duplication.

Members of the CCOCS Advisory Committee, led by Roy West (Memorial University), have formed the basis of the surveillance theme working group of the Canadian Strategy for Cancer Control. This working group will deal with the surveillance needs of the topic working groups within the Strategy. The collaboration between the two initiatives will ensure continuity and enhancements to both initiatives and maximize the results of CCOCS activities underway at present.

### **Conclusion**

The CCOCS has had its share of successes while at the same time overcoming many challenges and changes. An important factor in its success is the synergistic links that have been formed with key cancer stakeholders from across the country, all of whom are committed to the vision of creating a national cancer surveillance system. As well, agreements are continuing to be made between federal, provincial and territorial governments to collect and maintain relevant cancer information and databases according to a common set of definitions and quality standards.

Challenges remain in advocating the necessary resources, system development and information sharing needed for surveillance. It is anticipated that the collaboration with the Canadian Strategy for Cancer Control and the Canadian Association of Provincial Cancer Agencies will be instrumental in this domain.

The CCOCS is aware that more individuals, groups and organizations need to be informed of the overall objectives and specific activities of the CCOCS, and to this end a concerted effort is being made in the area of communications. ■

## Status Report

# Canadian Association of Provincial Cancer Agencies

Donald R Carlow

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The Canadian Association of Provincial Cancer Agencies (CAPCA) is a national organization consisting primarily of provincial cancer agencies. Having evolved gradually over the past 20 years, it recently became a formalized organization committed to making a significant contribution to Canada's overall cancer control effort. The purpose of this status report is to provide information about CAPCA, its history, what it is, what it does, where it is going and some indication of how it will get there. Although still in its early stages, the Association has great potential to make a significant impact on cancer control in Canada.

### Role of Provincial Cancer Agencies

In order to understand CAPCA's potential, it is important to know the role and function of individual provincial cancer agencies throughout Canada. Seven of the ten Canadian provinces have formally structured provincial cancer agencies, most of which are responsible for a provincial system of cancer control. In general, these provincial systems usually embody the following goals in their missions.

Reducing the incidence of cancer

Reducing mortality from cancer

Improving the quality of life of those living with cancer

For the most part, these agencies apply knowledge and best practices to a spectrum of activities, including prevention, screening, diagnosis, treatment, rehabilitation/support and palliative care. They also carry out professional, technical, patient and public information activities as well as conducting significant levels of basic research, translational research, clinical research and population-based epidemiologic research. All of the foregoing is aimed at achieving the key elements of their missions. Many of the provinces have cancer acts that clearly define these responsibilities; those without cancer acts have government-approved mandates established under provincial societies' acts or other enabling legislation.

A few decades ago, most provincial cancer agencies were devoted largely to clinic-based, modality-oriented treatment, such as radiation and systemic therapy. There has been gradual progression toward developing population-based systems of cancer control and geographically distributed services, along with networks and linking systems to achieve consistent patient-centred, evidence-based care. Although the extent to which provincial cancer agencies have adopted this full population-based mandate still varies, there has been significant movement toward the full realization of such a system in most provinces, and this is occurring at an increasing rate.

In many respects, provincial cancer agencies can be seen as the driving force behind cancer control activities within each province. This is not to say that they perform all these activities alone. Rather, they work in an extensive number of collaborative relationships. For example, there are links with the Canadian Cancer Society in areas such as cancer prevention and cancer information, with various regional health authorities in delivering care outside the formal cancer system, with academic institutions in areas such as research and education, with hospice societies and palliative care associations in pain and symptom control and palliative care, and with host hospitals as they relate to the provision of diagnostic and support services.

### History of CAPCA

The Canadian Association of Provincial Cancer Agencies had its modest beginnings approximately 20 years ago when many of the western provinces saw the need to have provincial cancer agencies get together to discuss matters of common interest and to share issues and developments in the various provinces. In the mid-1980s other provinces joined, participating in a somewhat loosely structured organization that held annual meetings in different locations throughout the country. By the late 1980s all Canadian provinces were involved, and slowly the focus shifted to a more structured approach. Meetings then included information

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sharing, education, workload comparative data sharing, collaboration with national partners and policy development. Linkages were developed with many organizations such as the Cancer Bureau at Health Canada's Laboratory Centre for Disease Control and the Canadian Council on Health Services Accreditation, as it related to defined standards development for accreditation of provincial cancer agencies and cancer centres supported by trained accreditation surveyors.

CAPCA has actively participated in the Canadian Coalition on Cancer Surveillance [see related Status Report in this issue], a coalition concerned with developing, standardizing and integrating cancer control information. It has also been involved in recent collaborative efforts to establish the Canadian Strategy for Cancer Control [see related Status Report in this issue]. CAPCA has made submissions and representations to the emerging Canadian Institutes of Health Research for the possible establishment of an institute for cancer research. In addition, it has undertaken some cooperative activity in human resource planning for cancer services for Canada.

Considerable work has been done to develop interprovincial workload comparisons for a variety of services. This has enabled provincial cancer agencies to compare resource use, benchmark best practices, learn from each other and undertake initiatives in several provinces to improve practices. CAPCA has given significant input into other national initiatives, such as the standards developed by the Canadian Association of Psychosocial Oncology and the cancer staging project undertaken by the Canadian Committee on Cancer Staging with financial support from the Canadian Cancer Society and the National Cancer Institute of Canada (CCS/NCIC).

It has also been encouraging to see the development of key groups within CAPCA. Collaborating with the CCS/NCIC, a research group has met on several occasions in connection with CAPCA's annual meeting. Recently, a systemic therapy group was established, which is devoted to developing consistent standards for chemotherapy administration across Canada.

Recognizing that the Association could contribute even more to the development of cancer control in Canada, CAPCA decided to become more formal, to establish more clearly its mission and vision and to define a board and policy-setting structure. A landmark meeting in Vancouver in February 1998 accomplished the initial work on a mission and vision, which served as the basis for developing a formal set of bylaws for the Association that were recently approved under the *Canada Corporations Act*. This led to the first formal meeting of the Board of Directors in Quebec City on October 28, 1999.

## **Mission**

The Canadian Association of Provincial Cancer Agencies is a national organization representing

provincial and territorial agencies engaged in cancer control. CAPCA exists to support the reduction of the burden of cancer through effective leadership, collaboration, communication and advocacy for cancer control.

The mission of CAPCA will be achieved through these activities.

Providing leadership in the coordination of cancer control matters as the national voice of organized cancer control development and program delivery

Promoting the collaborative development and adoption of standards and guidelines for all aspects of cancer control

Contributing to the development and implementation of a national cancer control strategy

Advocating organized cancer control nationally and provincially

Collaborating with other organizations to advocate public policy change to improve cancer control

Effectively communicating and working with key partners such as the CCS/NCIC, Health Canada and the Council of Deputy Ministers of Health

## **Vision**

While further elaboration of CAPCA's vision will take place over the next months, it is clear that our provincial cancer agencies, individually and collectively, are a significant part of Canada's effort to reduce the burden of cancer throughout this country. They are a significant source of new knowledge about cancer, including new developments and more effective means to prevent, diagnose and treat this disease. Cancer agencies are the main providers of advances in cancer control to patients, families and the public and, as well, they are the major providers of education for health care professionals, patients and families. Cancer agencies and their centres are not only local and regional resources, but through their collective efforts, are an important national resource capable of contributing far beyond what they do within their own jurisdictions. In many respects, provincial cancer agencies embody those steps concerned with translating research into policy and practice, as they carry out cancer control activities within each of the provinces.

It is important to understand that the existence of provincial cancer agencies in seven out of ten provinces is unique in comparison with other countries. Developing a national cancer strategy with clear goals and specific directions, linked to an already existing well-developed system for implementation, provides an unparalleled opportunity for Canada to have a model system of cancer control delivery with outcomes that cannot be matched anywhere else in the world.

The vision for CAPCA will be underpinned by the key principles outlined below.

An understanding of the profound and universal impact of cancer and the importance of an invincible alliance among agencies, centres, constituents and collaborators—in other words, CAPCA cannot fulfill its mission alone and will work with many others

Recognition of the importance of unity and common purpose to enable CAPCA and its partners to make significant contributions to cancer control

A continuing ability to enhance the linkage between research, policy and practice as a fundamental tenet of cancer control

An understanding that an effective cancer care delivery system is an important element of cancer control

Elements of the vision that have been under active discussion include the following.

CAPCA will function as a multi-centre, multi-nodal, virtual, national organization linked by common strategies, policies, standards and practices for cancer control and supported by unifying structures that include the effective application of technology

CAPCA will strive to achieve consistent standards of cancer control and care with the best practices of its constituents moved up to the national level and consistently applied across all provinces

CAPCA will develop effective mechanisms for the consistent dissemination of standards and information that will translate into practice

With the realization of this vision, Canada has an opportunity to achieve significant improvements in cancer outcomes and could be seen by the rest of the world as an example of a model system of cancer control—a standard by which other systems could be measured.

## Membership

CAPCA's membership includes active and associate members. Active members are all the provincial cancer agencies and other provincial and territorial organizations with similar responsibilities for cancer control. Associate members include organizations or agencies involved in cancer control, the CCS/NCIC being a prime example.

## Board of Directors

Each active member organization is entitled to appoint to the Board one director who is either its chief executive officer or another senior staff member. Associate members shall be entitled to elect two directors from among their respective boards or senior staff. The Board of Directors includes three trustees drawn from the boards of provincial cancer agencies and appointed by the committee of trustees that serves CAPCA.

The Board structure was formally defined at its first meeting in Quebec City, as outlined in Table 1.

<b>TABLE 1</b> <b>Structure of CAPCA's Board of Directors</b>
<p><b>Officers</b></p> <p>Chair — Peter Crossgrove, Cancer Care Ontario            Vice-chair — Rick Hester, CancerCare Manitoba            Secretary-Treasurer — Andrew Padmos, Cancer Care Nova Scotia</p>
<p><b>Active members</b></p> <p>Bertha Paulse — Newfoundland            Andrew Padmos — Nova Scotia            Eshwar Kumar/Louis-Marie Simard (will alternate) — New Brunswick            Luc Deschênes — Quebec            Dagny Dryer — Prince Edward Island            Ken Shumak — Ontario            Brent Schacter — Manitoba            Bob Allen — Saskatchewan            Jean-Michel Turc — Alberta            Donald Carlow — British Columbia (and chief executive officer)</p>
<p><b>Associate members</b></p> <p>To be formally appointed</p>

The chair of the Board is a trustee appointed by the Board on the recommendation of the committee of trustees. The executive committee of the Board comprises the three officers and the chief executive officer.

## Initial Activities

CAPCA is in the early stages of its development. There are several ongoing Canadian initiatives that could have an impact on CAPCA's future, such as outcomes of the Canadian Strategy for Cancer Control and the possibility of an institute for cancer research within the Canadian Institutes of Health Research. Under these circumstances, CAPCA will approach the next stage of its evolution in a manner that is flexible and adaptable, and its initial resource requirements will be modest. The head office will be located first in British Columbia. Many of CAPCA's goals will be achieved through a decentralized approach wherein activities will occur throughout Canada in a balanced, equitable and well-coordinated manner. In effect, it will be a virtual organization linking the various components together.

Initial activities will include further developing of revenue for start-up based upon a membership dues structure; creating the head office with space, equipment, technology support, Web site and key staff; and establishing board committees, structures and processes. A major activity will be establishing a process to develop national treatment policies, guidelines and protocols. It is our hope that CAPCA can become the home for several important national initiatives in areas such as radiation therapy, systemic therapy and human resource planning

as well as making links with other national organizations.

CAPCA will undertake significant coordinated initiatives in research, monitoring and surveillance; developing standards, strategy and policy; planning and coordinating human resources; disseminating information; establishing partnerships; developing mechanisms for patient and public input; and establishing key relationships with patient and public advocacy groups. It will also work with primary partners

such as the Canadian Strategy for Cancer Control, federal health authorities, the Council of Deputy Ministers of Health, the Canadian Institutes of Health Research, the CCS/NCIC, the Association of Canadian Medical Colleges, the Canadian Council on Health Services Accreditation, the Canadian Coalition on Cancer Surveillance, the Canadian Committee on Cancer Staging and many others. CAPCA will work toward establishing important international connections so that it may learn from other countries and contribute to worldwide efforts in cancer control. ■

## Status Report

# National Enhanced Cancer Surveillance System: A Federal-Provincial Collaboration to Examine Environmental Cancer Risks

Kenneth C Johnson

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The Laboratory Centre for Disease Control at Health Canada is the steward of the National Enhanced Cancer Surveillance System. The system was developed in the mid-1990s through a successful federal-provincial collaboration between the Environmental Risk Assessment and Case Surveillance Division (Cancer Bureau) and the provincial cancer registries.<sup>a</sup>

The central component of the National Enhanced Cancer Surveillance System was built by collecting detailed, risk factor questionnaire information from a Canada-wide sample of 20,755 recently diagnosed patients with cancer (18 types) and 5,039 population controls. The data set includes over 1,000 cases of 11 major types of cancer in Canada and up to 700 cases of some rarer forms of cancer. In parallel, the Environmental Quality Database was developed to facilitate examination of the relationships between cancer and the quality of air and water in Canada. Geographic evaluation of national cancer incidence data (e.g. assessments of cancer cluster findings) and a communication component complete the system.

Data collected under the National Enhanced Cancer Surveillance System serve the national public health interest and disease surveillance by facilitating analyses to improve our knowledge of the role of environmental factors as influences on cancer in Canada. These data also allow the study of behavioural risk factors.

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<sup>a</sup> The Canadian Cancer Registries Epidemiology Research Group comprises a principal investigator from each of the provincial cancer registries involved in the National Enhanced Cancer Surveillance System: Bertha Paulse (Newfoundland Cancer Foundation), Ron Dewar (Nova Scotia Cancer Registry), Dagny Dryer (Prince Edward Island Cancer Registry), Nancy Kreiger (Cancer Care Ontario), Eric Kliewer (CancerCare Manitoba), Diane Robson (Saskatchewan Cancer Foundation), Shirley Fincham (Division of Epidemiology, Prevention and Screening, Alberta Cancer Board) and Nhu Le (British Columbia Cancer Agency).

The National Enhanced Cancer Surveillance system can facilitate quick, yet thorough, analyses of cancer–environment issues that are important to the Laboratory Centre for Disease Control in its role as a key player in disease surveillance. A wide variety of analyses are now underway both federally and provincially. Below are two examples of analyses of considerable importance at Health Canada.

### Passive and Active Smoking and Breast Cancer

Of particular interest are the provocative results described in the recently published article “Passive and Active Smoking and Breast Cancer in Canada, 1994–97” (see below). The article contributes to the emerging evidence suggesting a link between second-hand tobacco smoke and breast cancer. If the relationships suggested by this analysis and six other related published studies are confirmed, environmental tobacco smoke could prove an important breast cancer risk factor.

### Chlorination of Drinking Water and Cancer Risk Assessment

Analyses are also underway to examine the association between chlorination disinfection by-products (CDBPs) in drinking water and bladder cancer, to support the current Health Canada (Health Protection Branch) initiative to re-evaluate national drinking water guidelines for CDBPs. This will be the first instance of a thorough analytic epidemiologic study being undertaken to examine the relationship between CDBPs and cancer in Canada, for locations outside of the province of Ontario. Additionally, by linkage to sophisticated water sampling analyses done by Health Canada’s Environmental Health Directorate, the system can produce epidemiologic analyses of specific CDBPs that have never been evaluated in this detail. Finally, the system allows for detailed study of more than a dozen other cancers and CDBPs, many of which have never been examined in depth anywhere in the world.

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#### Author References

Kenneth C Johnson, Environmental Risk Assessment and Case Surveillance Division, Cancer Bureau, Laboratory Centre for Disease Control, Health Canada, Tunney’s Pasture, Address Locator: 0601C1, Ottawa, Ontario K1A 0L2; E-mail: Ken\_LCDC\_Johnson@hc-sc.gc.ca

## Collaborative Research Opportunities

If you are interested in receiving more information on the data access policy and procedures or would like to discuss possible analyses using data from the National Enhanced Cancer Surveillance System data, please contact Ken Johnson (see Author References).

## Selected Recently Published Journal Articles

Johnson KC, Mao Y, Argo J, Dubois S, Semenciw R, Lava J. **The National Enhanced Cancer Surveillance System: a case-control approach to environment-related cancer surveillance in Canada.** *Environmetrics* 1998;9:495–504.

Mao Y, MacNeill IB, eds. **Proceedings of the Workshop on Retrospective Exposure Assessment Using Emission Inventories.** *Environmetrics* 1998;9(5):493–598.

Villeneuve PJ, Johnson KC, Kreiger N, Mao Y, and the Canadian Cancer Registries Epidemiology Research Group. **Risk factors for prostate cancer: results from**

**the Canadian National Enhanced Cancer Surveillance System.** *Cancer Causes Control* 1999;10(5):355–67.

Johnson KC, Hu J, Mao Y, and the Canadian Cancer Registries Epidemiology Research Group. **Passive and active smoking and breast cancer risk in Canada, 1994–97.** *Cancer Causes Control.* 2000;11:211–21.

Parkes R, Kreiger N, James B, Johnson KC. **Effects on subject response of information brochures and small cash incentives in a mail-based case-control study.** *Ann Epidemiol* 2000;10(2):117–24.

Srivastava A, Kreiger N. **Relation of physical activity to risk of testicular cancer.** *Am J Epidemiol* 2000;151(1):78–87.

Villeneuve PJ, Johnson KC, Hanley AJG, Mao Y, and the Canadian Cancer Registries Epidemiology Research Group. **Alcohol, tobacco and coffee consumption and the risk of pancreatic cancer: results from the Canadian Enhanced Surveillance System case-control project.** *Eur J Cancer Prev* 2000;9:49–58. ■

## Announcement

### Formation of the Canadian Prostate Cancer Research Initiative

The Canadian Prostate Cancer Research Initiative (CPCRI) has been formed in direct response to recommendations from the National Forum on Prostate Cancer in 1997. The CPCRI is an alliance among Health Canada, the National Cancer Institute of Canada, the Canadian Cancer Society and the Canadian Prostate Cancer Network. Its purpose is to strengthen existing capacities and stimulate new efforts across Canada in prostate cancer research, with an emphasis on strategic initiatives to fill gaps, build capacity in important research areas and to respond to unique opportunities.

The Board of Directors, representing the founding partners, will provide governance and strategic direction and will seek additional funding sources for prostate cancer research. The Management Committee will direct the Initiative's research programs by establishing research priorities and policies, overseeing the scientific review process, making research funding recommendations and raising awareness of issues surrounding prostate cancer research.

The Management Committee includes community representatives and expertise from the range of professional disciplines involved in prostate cancer research (laboratory science, radiation oncology, surgical oncology, medical oncology, epidemiology, behavioural science and health policy). Current members are George E Connell (Chair), Marvin Brodsky, Lorna Butler, Yves Fradet, Mary Gospodarowicz, Charles Hollenberg, Robert Kerbel, François Meyer, Peter M Venner, George Richards and David Brittain.

*For information about the CPCRI, please contact Gareth Taylor at (416) 934-5656.*

## Book Reviews

# Health Promotion Planning: An Educational and Ecological Approach (third edition)

By Lawrence W Green and Marshall W Kreuter

Mountain View (California): Mayfield Publishing Company, 1999;  
xxxi + 621 pp; ISBN 0-7674-0524-2; \$98.95

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*Health Promotion Planning: An Educational and Ecological Approach* is the third edition of a book that has been a core reference on health promotion planning for the past 10 years. This edition, like the others, is based on the PRECEDE-PROCEED framework. It uses an analytic approach to help planners decide what health issues to address and how to address them. This is a challenging task given the complexity of planning using the health promotion principles of community involvement and comprehensive, effective response to community needs. The book provides a specific approach with detailed steps to accomplish this task.

The framework around which the book is built starts with a social assessment of the factors influencing the quality of life of the population, followed by an epidemiologic assessment of the health issues affecting quality of life. Phase 3 is a behavioural and environmental evaluation of the factors influencing the health and health problems of the population. In Phase 4 an educational and ecological assessment is done to identify the predisposing, enabling factors influencing both behaviour and lifestyle and the environment. At this point, program priorities, targets and objectives have been identified; in Phase 5 the key administrative and policy factors are identified to assist the planner to develop programs that will have the greatest chance of success. The final four phases involve implementation and conducting evaluations of the process, impact and outcomes.

The book is organized into five sections: an overview of health promotion and the framework; a chapter on each of the five assessment planning phases; a chapter on evaluation basics; a chapter on specific applications of the planning framework in each of four settings—community, occupational, school and health care; and a final new chapter on a computer application of the framework called EMPOWER. Each chapter has exercises and a detailed list of references. The glossary at the end assists the reader to navigate through sometimes confusing terminology.

The authors take an academic, thoughtful approach to presenting the information in the book. The rationale for each step as well as the theoretical and research basis are

included in each chapter. This is nicely balanced with attention to the practical realities of working in the complexities of “real life”. The authors do not shy away from stating their values. Although these may not be shared by everyone, their inclusion points to the need to include a values discussion in every planning exercise.

While this book provides steps in each planning phase, it is not a simple “how to” book. It presents options for consideration by planners as they tailor their own process. This is one of the book’s strengths, but readers must be prepared to exercise their own judgement and use their own experience to make the best use of it. Readers will find this book most useful as a reference to which they can turn during the course of a planning exercise. It is possible to use it starting at any of the points in the five-stage assessment process, although the authors do repeatedly emphasize that unless program decisions are grounded in meeting real community needs, they may not be effective.

The book will appeal to a wide range of individuals involved in health promotion planning. It takes a broad view of health promotion activities, from those directed at underlying determinants such as poverty to specific interventions in the health care setting. This comprehensiveness is a valuable aspect to the book because practitioners in different settings can identify both the similarities and differences in their practice. The book would be very useful for an academic course in health promotion planning at either the senior undergraduate or graduate level.

While much of the third edition has material that was available in the previous edition, there is enough new material to make it a good buy for even those who have the previous text. For example, the addition of the word “ecological” in the title is a good example of how the authors have incorporated recent thinking into this edition. The reference list includes many new references, and it is very useful to have many of the key health promotion references listed in one place.

**Overall rating:** Excellent

**Strengths:** Broad approach to health promotion that reflects recent thinking in the field  
Uses a systematic, logical approach to planning  
Strong theoretical and research basis  
Includes evaluation as an essential component of program planning  
Includes examples of the use of the planning framework in "real life" situations  
Gives options and rationale for each planning phase to support a tailored approach

**Weaknesses:** Dense nature of the text itself (so much information at such a significant depth could benefit from a larger page and font to facilitate the ease of reading)  
Some sections have less detail than others

**Audience:** Health promotion program planners and managers; public health and community health service providers; federal, provincial/territorial, regional government health departments; non-governmental organizations; students and educators in senior undergraduate and postgraduate health programs in universities and colleges; researchers

**Paula J Stewart**

Paula J Stewart & Associates  
Community Health Consultant  
1093 Chablis Park  
Orleans, Ontario K1C 2T5

# Quantitative Estimation and Prediction of Human Cancer Risks

IARC Scientific Publications No 131

Edited by S Moolgavkar, D Krewski, L Zeise, E Cardis and H Møller  
Lyon (France): International Agency for Research on Cancer, 1999;  
xiii + 322 pp; ISBN 92-832-2131-1; \$122.50

This volume from the International Agency for Research on Cancer consists of nine papers by different authors, each of which provides a discussion of an aspect of cancer risk assessment.

The relationship between exposure to risks and the development of cancer at a particular site in a human is seldom known with any degree of precision. This is so partly because understanding of the mechanics of carcinogenesis is not complete. Also, dose-response curves for most carcinogens and most human cancer sites are not well understood. Extrapolation from animal experiments using high levels of exposure to humans affected by low levels of exposure is often open to question. The synergistic effects of exposures to multiple risks are poorly understood.

Another point to be considered is the fact that long latencies are associated with most cancers, and assessing the effects of exposures in the distant past is problematic. Estimating the exposure dose of most individuals to most carcinogens is an imprecise science. Furthermore, the reasons why some humans are more susceptible than

others to the development of malignant tumours at certain sites are in the early stages of study. With some notable exceptions, cigarette smoking being one, the relative risks of everyday exposures tend to be small and difficult to measure with sufficient precision to distinguish between a small effect and no effect, which adds another layer of complexity to the problem of quantifying risk effects.

Nevertheless, many carcinogens have been identified. Regulations regarding manufacturing, distribution and use of many of these substances are in place, at least in developed parts of the world. However, even though a substance is known to be a carcinogen, it will not necessarily be banned from manufacture or use. For example, it is possible for a pesticide to be implicated in causing cancer and yet still be widely used because of its value in enhancing crop yields. When deciding upon regulation of a substance, regulatory agencies must take into account economic impact as well as carcinogenic risk.

The fact that regulation, not necessarily prohibition, of carcinogens must be carried out in the face of great complexity in the exposure/outcome relationship,

requires that “quantitative estimation and prediction of human cancer risks” at least be attempted. This book essentially surveys the current state of the science. The following chapter titles reveal the extent of the work reviewed in the volume.

1. “Quantitative estimation and prediction of human cancer risk: its history and role in cancer prevention”
2. “Quantitative estimation and prediction of cancer risk: review of existing activities”
3. “Principles of the epidemiological approach to QEP” [quantitative estimation and prediction of human cancer risk]
4. “Measurement of exposure and outcome in epidemiological studies used for quantitative estimation and prediction of risk”
5. “Long- and medium-term carcinogenicity studies in animals and short-term genotoxicity tests”
6. “Empirical approaches to risk estimation and prediction”

7. “Mechanisms of carcinogenesis and biologically based models for estimation and prediction of risk”
8. “Review of specific examples of QEP”
9. “Future perspectives, unresolved issues and research needs”

This volume shows the effects of taking considerable care in preparation and editing. Hence, without undue struggle, the reader will be able to gain an appreciation of the problems, complexity and progress associated with the various aspects of cancer risk assessment. The extensive bibliography included in each chapter will allow those with a thirst for deeper insight into quantitative estimation and prediction of human cancer risk than is provided in this admirable volume to go to the literature and slake that thirst.

**Ian B MacNeill**

Professor Emeritus  
Department of Statistical and Actuarial Sciences  
University of Western Ontario  
London, Ontario N6A 5B7

## Epidemiology of Childhood Cancer

IARC Scientific Publications No 149

By Julian Little

Lyon (France): International Agency for Research on Cancer, 1999;  
xiv + 386 pp; ISBN 92-832-2149-4; \$104.50

Although childhood cancer accounts for only about 1% of all cancers in Canada and even fewer deaths, its public health importance is high, in part because of the long-term health implications for survivors. Childhood cancer differs in many ways from its adult counterpart, including site of occurrence, as well as histologic and clinical behaviour, and thus needs to be considered separately. Though there are many useful textbooks about the epidemiology of cancer, *Epidemiology of Childhood Cancer* is the first to synthesize and describe the various aspects of childhood cancer epidemiology in one monograph.

An overview of design issues relating to the conduct of epidemiologic studies is presented in Chapter 1, including the consideration of alternative explanations for study findings. Several current hypotheses relating to complex routes of exposure for some childhood cancer risk factors are also briefly discussed. Two examples are Greaves' hypothesis on population mixing and acute lymphocytic leukemia, and the relation of N-nitroso compounds to brain tumours.

The second chapter covers the descriptive epidemiology of childhood cancer and is organized according to the histology-based Birch and Marsden (Manchester) classification system. For each diagnostic group, geographical patterns, age-specific incidence and sex ratios, ethnic origin and time trends are described. Additionally, variation in rates according to socio-economic status as well as other spatial and temporal clustering are defined where applicable. Finally, for certain childhood cancers, distinct epidemiologic features are discussed such as skeletal subtype distribution for osteosarcomas.

Chapters 3–10 present the current knowledge of major risk factors for childhood cancer, organized by exposure rather than cancer type. Chapter 3 focuses on genetic factors and the proportion of each cancer type believed to be the consequence of specific genetic syndromes and/or familial aggregations. Unfortunately, this chapter suffers from the limitations of any text about a fast developing area, in that it is already out of date.



Chapters 4 and 5 examine particular exposures in relation to childhood cancer risk. First, the effects of ionizing radiation on childhood cancer outcomes (mostly leukemia) are discussed in Chapter 4. Specific examples of residential exposure from both point source (i.e. bombs, nuclear plant accidents) and diffuse origin (i.e. nuclear installations, background radiation) are reviewed. Then Chapter 5 provides a detailed discussion of EMF (electromagnetic field) exposure assessment as well as a review of pertinent studies.

The associations between paternal occupational and environmental exposures to chemicals and dusts are addressed in Chapter 6. Most studies have focused on the positive association with leukemia, though the few studies examining other childhood cancers are also reviewed here.

The seventh chapter discusses the hypothesis that childhood cancer risk is related to maternal and infant infection. Most of this text reviews studies on leukemia, though there are small sections on lymphoma, brain tumours and other childhood cancers. Maternal and paternal lifestyle habits and their association with cancer in the offspring are examined in the next chapter, including diet and vitamin supplements, as well as tobacco, alcohol and recreational drug use. Associations between specific types of childhood cancer and maternal age, birth order and prior reproductive history are considered in Chapter 9, while the index child's medical history in relation to cancer risk is discussed in Chapter 10.

The final Chapter 11 summarizes the evidence on risk factors for each diagnostic group according to the strength of published findings, based loosely on the Brandford-Hill criteria. The chapter contains excellent reference tables outlining the evidence for leukemias,

lymphomas, central nervous system tumours, neuroblastoma and Wilms' tumour. The continuing problems of accurate and valid exposure assessment and non-biased selection of control subjects are addressed. The authors assert that objective markers of exposure need to be developed and used in more epidemiologic studies. Furthermore, adequate sample sizes for subtype analysis require the involvement of co-operative groups, and studies should be expanded to include subjects from outside North America and Europe.

This book is an excellent primer for anyone contemplating research into the epidemiology of childhood cancer. The review of etiologic studies is exhaustive and critical, though an update will need to be done shortly as the monograph only includes studies published before mid-1997. In such a quickly evolving field, especially when combined with molecular biology, regular updates are necessary. Moreover, the monograph should expand its discussion of biologic mechanisms; though mentioned in certain sections, a separate chapter may be useful. Nonetheless, *Epidemiology of Childhood Cancer* is an extremely thorough and well-documented reference book including clear and detailed tables and an extensive bibliography. It should be included in the library of anyone interested in childhood cancer epidemiology.

### Amanda Shaw

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## New Resources

### **NOTICE!** **Canadian Cancer Statistics 2000**

National Cancer Institute of Canada  
Toronto (Ontario), 2000

*Canadian Cancer Statistics 2000* is now accessible on the Internet at <[www.cancer.ca/stats](http://www.cancer.ca/stats)>.

You can download and/or print any sections, graphs, tables, etc. or all of this document from the above Web site.

*If you would like to receive a hard copy of this publication, contact*

your local office of the Canadian Cancer Society,  
your regional office of Statistics Canada

or

Canadian Cancer Society (National Office)  
10 Alcorn Avenue, Suite 200  
Toronto, Ontario M4V 3B1  
Tel: (416) 961-7223  
Fax: (416) 961-4189  
E-mail: [stats@cancer.ca](mailto:stats@cancer.ca)

### **National Population Health Survey Highlights No 2: Physical Activity of Canadians**

Health Canada  
Ottawa (Ontario), 1999

Health Canada has released the *National Population Health Survey Highlights No 2: Physical Activity of Canadians*, which is based on results from cycle 2, 1996/97 of the National Population Health Survey (NPHS). The Highlights series was developed to provide descriptive information on health issues covered by the NPHS. Several groups within and outside of Health Canada contributed to the development of *Highlights No 2*, including the Fitness and Active Living Program Unit of the Health Promotion and Programs Branch, the Cancer Bureau and the Bureau of Cardio-respiratory Disease and Diabetes at the Laboratory Centre for Disease Control, and the Canadian Fitness and Lifestyle Research Institute.

*Highlights No 2* and supplementary data tables are also available on the Cancer Bureau's Web site at <[www.hc-sc.gc.ca/hpb/lcdc/bc/nphs/index.html](http://www.hc-sc.gc.ca/hpb/lcdc/bc/nphs/index.html)>.

*If you would like to receive a hard copy of this package, contact*

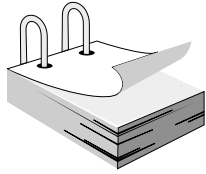
Cancer Bureau  
Laboratory Centre for Disease Control  
Health Canada, Tunney's Pasture  
Address Locator: 0602E2  
Ottawa, Ontario K1A 0L2

### **University of Ottawa Community Medicine Residency Program alumni(ae) to hold reunion breakfast at CPHA Annual Conference 2000**

Between 1977 and 1998, the Community Medicine Residency Program at the University of Ottawa provided training in public health, offering unique opportunities for Community Medicine residents to work at federal and international levels as well as local levels. Sadly, that experience is no longer as readily available to the current generation of trainees, but the dozens of practitioners who went through the Program continue to extend its impact through their research, teaching and practice in Canada and abroad.

The Canadian Public Health Association (CPHA) is holding its 91st annual scientific conference and general meeting in Ottawa from October 22 to 25, 2000. What better opportunity for former residents to return to Ottawa and celebrate this formative experience, meet with colleagues and staff and learn about the new Institute of Population Health; there may even be new facilities to tour. Watch for the conference program to see the details about our alumni(ae) breakfast, and **please let us know if you are planning to join us.**

Best regards,  
Chris Mills (cohort of 1990)  
E-mail: [Christina\\_Mills@hc-sc.gc.ca](mailto:Christina_Mills@hc-sc.gc.ca)



# Calendar of Events

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<b>May 7–10, 2000</b> <b>Victoria, British Columbia</b>	<p>“Science and Policy in Action” First International Conference on Women, Heart Disease and Stroke Heart and Stroke Foundation of Canada, American Heart Association, Health Canada, Centers for Disease Control and Prevention and Canadian Cardiovascular Society</p>	<p>Taylor &amp; Associates 18 – 5370 Canotek Road Gloucester, Ontario K1J 9E8 Tel: (613) 747-0262 Fax: (613) 745-1846 E-mail: <a href="mailto:gtaylor@netrover.com">gtaylor@netrover.com</a> &lt;<a href="http://www.hsf.ca/women&amp;cvd2000">www.hsf.ca/women&amp;cvd2000</a>&gt;</p>
<b>May 7–10, 2000</b> <b>Ottawa, Ontario</b>	<p>“Exposure Assessment for Disinfection By-products in Epidemiologic Studies: An International Workshop” Sponsored by Health Canada and the US Environmental Protection Agency</p>	<p>Tye Arbuckle Bureau of Reproductive and Child Health Laboratory Centre for Disease Control Health Canada, Tunney’s Pasture Address Locator: 0701D Ottawa, Ontario K1A 0L2 E-mail: <a href="mailto:Tye_Arbuckle@hc-sc.gc.ca">Tye_Arbuckle@hc-sc.gc.ca</a> &lt;<a href="http://www.hc-sc.gc.ca/hpb/lcdc/events/expo2000/index.html">www.hc-sc.gc.ca/hpb/lcdc/events/expo2000/index.html</a>&gt;</p>
<b>May 17–19, 2000</b> <b>Denver, Colorado</b> <b>USA</b>	<p>“Health Promotion Excellence in the New Century: Ascending New Heights” 18<sup>th</sup> National Conference on Health Promotion and Public Health Education <i>and</i> the 2000 SOPHE Midyear Scientific Meeting Sponsors: Centers for Disease Control and Prevention, Association of State and Territorial Directors of Health Promotion and Public Health Education and Society for Public Health Education</p>	<p>&lt;<a href="http://www.sophe.org">www.sophe.org</a>&gt; &lt;<a href="http://www.astdhpphe.org">www.astdhpphe.org</a>&gt;</p>
<b>May 28–30, 2000</b> <b>Ottawa, Ontario</b>	<p>“Charting the Course for Literacy and Health in the New Millennium” First Canadian Conference on Literacy and Health Organized by the Canadian Public Health Association’s National Literacy and Health Program</p>	<p>CPHA Conference Department 400 – 1565 Carling Avenue Ottawa, Ontario K1Z 8R1 Tel: (613) 725-3769 Fax: (613) 725-9826 E-mail: <a href="mailto:conferences@cpha.ca">conferences@cpha.ca</a> &lt;<a href="http://www.nald.ca/nlhp.htm">www.nald.ca/nlhp.htm</a>&gt;</p>
<b>June 11–13, 2000</b> <b>Edmonton, Alberta</b>	<p>“Statistics and Health 2000” International conference organized by the Biostatistics Research Group (BRG), Statistics Centre, University of Alberta</p>	<p>KC Carrière (Program Committee Chair) Tel: (780) 492-4230 Fax: (780) 492-6826 E-mail: <a href="mailto:BRG@stat.ualberta.ca">BRG@stat.ualberta.ca</a> &lt;<a href="http://www.stat.ualberta.ca/~brg">www.stat.ualberta.ca/~brg</a>&gt;</p>
<b>June 14–18, 2000</b> <b>Ottawa, Ontario</b>	<p>“Beyond 2000: Healthy Tomorrows for Children and Youth” Conference hosted by the Canadian Institute of Child Health, the Canadian Paediatric Society and the Canadian Academy of Child Psychiatrists</p>	<p>Jackie Millette Manager, Education Department Canadian Paediatric Society 100 – 2204 Walkley Road Ottawa Ontario K1G 4G8 Tel.: (613) 526-9397, ext 228 Fax: (613) 526-3332 E-mail: <a href="mailto:jackie@cps.ca">jackie@cps.ca</a> &lt;<a href="http://www.cps.ca/beyond2000">www.cps.ca/beyond2000</a>&gt;</p>

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<p><b>June 15–17, 2000</b>  <b>Seattle, Washington</b>  <b>USA</b></p>	<p>33<sup>rd</sup> Annual Meeting of the Society for  Epidemiologic Research</p>	<p>Jacqueline C Brakey  Registration Co-ordinator, Conferences  University of Utah  Tel: (801) 581-5809  Fax: (801) 581-3165  E-mail: jbrakey@admin.dce.utah.edu  &lt;www.conferences.utah.edu&gt;</p>
<p><b>June 20–22, 2000</b>  <b>Jonquière, Quebec</b></p>	<p>“From DNA to the Community: An International  Meeting on Community Genetics”  Sponsors: <i>Corporation de recherche et d’action  sur les maladies héréditaires</i> and Health  Canada</p>	<p>ID Rusen  Bureau of Reproductive and Child Health  Laboratory Centre for Disease Control  Health Canada, Tunney’s Pasture  Address Locator: 0701D  Ottawa, Ontario K1A 0L2  Tel: (613) 946-9742  Fax: (613) 941-9927  E-mail: ID_Rusen@hc-sc.gc.ca</p>
<p><b>July 3–7, 2000</b>  <b>Montreal, Quebec</b></p>	<p>IXth International Symposium in Medical  Geography  “An Agenda for the Geography of Health and  Health Care in the New Century”</p>	<p>Jean-Pierre Thouez  Département de géographie  Université de Montréal  C.P. 6128, succ. Centre-Ville  Montréal, Québec H3C 3J7  Tel: (514) 343-8054  Fax: (514) 343-8008  E-mail: geo2000@attcanad.net  &lt;www.attcanada.net/~geo2000&gt;</p>
<p><b>July 9–28, 2000</b>  <b>Newton Lower Falls,</b>  <b>Massachusetts</b>  <b>USA</b></p>	<p>Epidemiology Research Institute  20<sup>th</sup> Annual Epidemiology Summer Program</p>	<p>Epidemiology Research Institute  One Newton Executive Park  Newton Lower Falls, MA  USA 02462-1450  Tel: (617) 244-1200  Fax: (617) 244-2669  E-mail: info@epidemiology.com  &lt;www.epidemiology.com&gt;</p>
<p><b>August 6–11, 2000</b>  <b>Chicago, Illinois</b>  <b>USA</b></p>	<p>11<sup>th</sup> World Conference on Tobacco OR Health  Hosts: American Cancer Society, American  Medical Association and Robert Wood  Johnson Foundation</p>	<p>11<sup>th</sup> World Conference on Tobacco OR  Health  c/o American Medical Association  515 North State Street  Chicago, IL  USA 60610  Attn: Anne Jenkins, Conference Manager  Tel: (312) 464-9059  Fax: (312) 464-4111  E-mail: 11thwctoh@ama-assn.org  &lt;www.wctoh.org&gt;</p>
<p><b>August 23–27, 2000</b>  <b>Victoria, British Columbia</b></p>	<p>ITCH 2000: “From Potential to Practice”  International Conference on Information  Technology in Community Health</p>	<p>ITCH 2000  c/o School of Health Information Science  University of Victoria  PO Box 3050, STN CSC  Victoria, BC V8W 3P5  Tel: (250) 721-8576  Fax: (250) 472-4751  E-mail: itch@hsd.uvic.ca  &lt;www.itch.uvic.ca&gt;</p>

<b>October 22–25, 2000 Ottawa, Ontario</b>	"Health for All in the Year 2000" Canadian Public Health Association 91 <sup>st</sup> Annual Conference <i>and</i> Ontario Public Health Association 51 <sup>st</sup> Annual Conference	CPHA Conference Services 400 – 1565 Carling Avenue Ottawa, Ontario K1Z 8R1 Tel: (613) 725-3769 Fax: (613) 725-9826 E-mail: <a href="mailto:conferences@cpha.ca">conferences@cpha.ca</a> < <a href="http://www.cpha.ca">www.cpha.ca</a> >
<b>June 12–15, 2001 Toronto, Ontario</b>	Congress of Epidemiology 2001 Combined meeting of American College of Epidemiology, American Public Health Association's Epidemiology Section, Canadian Society for Epidemiology and Biostatistics and Society for Epidemiologic Research	< <a href="http://www.epi2001.org">www.epi2001.org</a> >
<b>July 1–6, 2001 Vancouver, British Columbia</b>	"Global Aging: Working Together in a Changing World" 17 <sup>th</sup> Congress of the International Association of Gerontology <i>Call for papers: June 1, 2000; Abstract deadline: December 31, 2000</i>	Congress Secretariat Gerontology Research Centre Simon Fraser University at Harbour Centre 2800 – 515 West Hastings Street Vancouver, BC V6B 5K3 Tel: (604) 291-5062 Fax: (604) 291-5066 E-mail: <a href="mailto:iag_congress@sfu.ca">iag_congress@sfu.ca</a> < <a href="http://www.harbour.sfu.ca/iag">www.harbour.sfu.ca/iag</a> >

***1999 Peer Reviewers***

We are extremely grateful to the following  
people for their enormous contribution  
to *Chronic Diseases in Canada* as  
peer reviewers in 1999.

- |                       |                      |
|-----------------------|----------------------|
| Alexander C Allen     | Joan Lindsay         |
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| Grace M Johnston      | Xiaodi Xie           |
| Judith Klotz          |                      |

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