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Agreement between proxy- and case-reported information obtained using the self-administered Ontario Familial Colon Cancer Registry epidemiologic questionnaire

Victoria Nadalin, Michelle Cotterchio, Gail McKeown-Eyssen and Steven Gallinger

Abstract

Case-control studies of fatal cancers often rely on proxy respondents. It is important therefore, to determine the completeness and accuracy of proxy-reported information. We evaluated proxy reports using the Ontario Familial Colon Cancer Registry epidemiology questionnaire. A proxy questionnaire was completed by spouses or relatives identified by a sample of participating cases. Item non-response and percentage agreement (between case and proxy reports) were assessed. More than 30% of proxies were unable to report on physical activity, gynecological surgery, alcohol intake, weight 20 years ago, and oral contraceptive use. Proxy reports of medical history and bowel screening varied, the percentage missing ranging from 5% for diabetes to 44% for familial polyposis in the case of medical history, and from 4% for colonoscopy to 27% for hemoccult tests in the case of screening. Agreement between case and proxy report was good to excellent for colonic screening, most medical history, and for reproductive, medication and vitamin use variables (74% to 100%). It is useful to collect proxy information on such variables as medical history, parity, colonic screening and vitamin use, whereas oral contraceptive use and previous weight are not well reported.

Key words: *colon cancer; data collection; epidemiology; proxy report*

Introduction

Case-control cancer studies often rely on proxy respondents to complete questionnaires about their deceased spouse or relative. Although the inclusion of proxy respondents increases the sample and provides a more representative study sample, missing data or inaccurate information reported by proxies can bias estimates of relative risk.[1] It is important to determine the completeness and accuracy of proxy-reported information because this will aid in the interpretation of data collected from proxies and in the design of proxy questionnaires.

The one- and two-year survival rates for colorectal cancer are 73% and 60% respectively.[2] Since a significant proportion of colorectal cancer patients will have died before contact can be made with them, colorectal cancer research that uses mailed, self-administered questionnaire data would benefit from an understanding of which risk factors and subject characteristics proxies can accurately report. Although several proxy validity studies using interview-administered questionnaires have been conducted, only one study has used self-administered questionnaires.[3] Furthermore, the accuracy of proxy-reported colonic screening information has never been evaluated.

The present study compared information provided by colorectal cancer patients and their proxies using the 32-page Ontario Familial Colon Cancer Registry (OFCCR) epidemiologic questionnaire. This questionnaire was developed by the Epidemiology Working Group of the US National Cancer Institute's Cooperative Family Registries for Colon Cancer Studies (CFRCCS) and includes colonic screening, medical history, lifetime physical activity, alcohol and cigarette consumption, vitamin and medication use, and demographic variables.

Materials and methods

Living colorectal cancer cases were sampled from the OFCCR, one of the six international sites of the CFRCCS. Since its inception in 1997, the OFCCR has been collecting family history, epidemiologic data and biologic material (blood and tumour blocks) from colorectal cancer patients and controls.[4] Following completion of the self-administered epidemiologic questionnaire, a sample of cases was telephoned and asked for oral consent to allow the mailing of a questionnaire to spouses or relatives. Identified proxies were then mailed a cover letter and proxy version of the epidemiologic questionnaire. Proxies were asked to complete the questionnaire about their spouse or relative, unassisted, and to return it in a postage-paid return envelope. The proxy questionnaire contained the same questions as the case questionnaire, with slightly different wording (e.g., "did your

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relative ever…" versus "did you ever…"). Two weeks after the questionnaire mailing, all proxies were mailed a reminder postcard and, after six weeks, non-respondents were telephoned and reminded to return the questionnaire.

Proxy item non-response (i.e., the percentage missing or unknown) was assessed for each of the main variables. Variables with more than 30% item non-response were excluded from further analysis of percentage agreement between proxy and case reports.

The percentage perfect agreement between proxy and case report was determined, and 95% confidence intervals were calculated. Variables with data reported for fewer than 10 case-proxy pairs were not evaluated. Dichotomous/nominal/ordinal responses were coded as in the original questionnaire, and the few continuous variables were categorized into tertiles.

The kappa statistic was not computed as a measure of agreement because disparate marginal probabilities (due to the small sample) in K × K tables often produce exceptionally low kappa coefficient estimates even though the percentage agreement is substantial.[6,7] Estimates of percentage agreement are presented, as this is a more reliable indicator of agreement when marginal probabilities are unequal. Pearson correlation coefficients for continuous variables are not presented, as this statistic measures association/co-variation, not agreement.[8] Perfect percentage agreement of greater than 80% was interpreted as excellent, between 61% and 80% was considered good, between 40% and 60% was considered moderate, and less than 40% was considered poor.[9]

Results

Of the 93 cases invited to participate in this sub-study, 74 (80%) consented to proxy contact, and 55 proxies (74%), 31 females and 24 males, returned their questionnaire. Proxies were predominantly spouses (70%) and relatives (25%).

Table 1 shows item non-response for case and proxy reports of each main variable in the OFCCR epidemiologic questionnaire. As expected, non-response by colon cancer

TABLE 1
Item non-response for case and proxy reports (% missing)

Variable*	Missing response (%)	
	Cases	Proxies
Colonic screening		
Ever had hemoccult test	5	27
Ever had sigmoidoscopy	4	15
Ever had colonoscopy	0	4
Medical history		
Ever diagnosed with familial adenomatous polyposis	15	44
Ever diagnosed with high triglycerides	4	31
Ever diagnosed with ulcerative colitis	5	27
Ever diagnosed with irritable bowel syndrome	5	27
Ever diagnosed with diverticular disease	2	25
Ever diagnosed with Crohn's disease	4	16
Ever diagnosed with polyps	0	15
Ever diagnosed with high cholesterol	0	15
Number of cancers diagnosed	4	13
Ever had part of large bowel or colon removed	4	9
Ever had gallbladder removed	0	7
Ever had diabetes	0	5
Medications and vitamin use		
Ever took calcium pills regularly	0	20
Ever took other laxatives regularly	4	18
Ever took folic acid regularly	5	18
Ever took aspirin regularly	0	16
Ever took acetaminophen regularly	0	16
Ever took ibuprofen medications regularly	4	16
Ever took multivitamins regularly	2	16
Ever took antacids regularly	2	16
Ever took bulk forming laxatives regularly	0	15
Alcohol intake		
Any alcohol consumed regularly in 20s	4	31
Number of years consumed alcohol in 20s	0	40
Number of beverages consumed/week in 20s	0	46
Any alcohol consumed regularly in 30s & 40s	2	20
Number of years consumed alcohol in 30s & 40s	0	29
Number of beverages consumed/week in 30s & 40s	4	31
Any alcohol consumed regularly 50+	4	19
Number of years consumed alcohol 50+	4	24
Number of beverages consumed/week 50+	2	26
Any alcohol consumed regularly, total	2	23

TABLE 1 *(cont'd)*
Item non-response for case and proxy reports (% missing)

Variable*	Missing response (%)	
	Cases	Proxies
Physical activity		
2/3 of physical activity questions, 20s	89	80
2/3 of physical activity questions, 30s	93	84
2/3 of physical activity questions, 50s	94	92
Demographic and other variables		
Income	9	26
Education	0	13
Ever smoked cigarettes, cigars or pipe	0	5
Marital status	0	2
Weight (current)	0	18
Weight 20 years ago	4	38
Menstruation, pregnancy and menopause†		
Ever took hormonal contraceptives	3	32
Ever took hormone replacement	6	26
Had a period in the last 12 months (menopausal status)	0	16
Ever been pregnant	0	3
Reproductive surgeries‡		
One or both ovaries removed, no hysterectomy	50	39
One ovary removed without hysterectomy	44	33
Both ovaries removed without hysterectomy	44	33
Hysterectomy with one or both ovaries removed	22	28
Simple hysterectomy	33	6

* n = 55 (except for female variables which are footnoted)
† n = 31
‡ n = 18

cases was quite low for the majority of variables, with the exception of physical activity and reproductive surgeries. However, item non-response for proxies ranged from 2% (marital status) to 92% (physical activity in the 50s age group). Proxy non-response varied for the three main colonic screening variables, ranging from 4% for colonoscopy to 27% for hemoccult test. Medical history information was generally reported by proxies with completeness, with the exception of high triglyceride diagnosis (31% missing), reproductive surgery details (6% to 39% missing), and familial adenomatous polyposis (44% missing). All of the medication use and vitamin supplement variables had reasonably low proxy non-response (16% to 20%). As evidenced by the large proportion of missing responses (ranging from 31% to 92%), many proxies were unable to report alcohol consumption (in the 20s), physical activity (in the 20s, 30s, 50s) and oral contraceptive use.

The percentage of perfect agreement between case and proxy reports is presented in Tables 2, 3 and 4. Agreement was excellent for most of the variables. The agreement between case and proxy report was good to excellent for the colonic screening variables (74% to 92%); agreement on indication for procedure (screen versus diagnostic) was also excellent (93%), and 95% of proxy case reports were concordant for age of first and last colonoscopy, indicating excellent agreement (data not shown). Proxy validity was excellent for medical history variables, ranging from 87% agreement with respect to high cholesterol and occurrence of polyps to 100% agreement for diabetes and the type of polyps diagnosed. Surprisingly, there was only 78% agreement between case and proxy report regarding knowledge of number of cancers diagnosed, although first cancer diagnosis did show excellent agreement (94%). Excellent agreement was also observed for vitamin, medication and any alcohol use with values ranging from 80% to 95%. Reproductive history variables also yielded excellent percentage agreement values (84% to 100%). Agreement for marital status was 98%, and it is interesting that agreement on education and income were only moderately concordant (68% to 71%).

Regarding the few variables on which the agreement between case and proxy report did not fall into the excellent category, proxies tended to both over- and under-report the information of interest with equal probability, with the following exception: proxies were more likely to over-report sigmoidoscopies (90% of the discrepant case-proxy reports). For number of cancers diagnosed, income and weight, discordant information fell close to the diagonal, indicating partial agreement.

Discussion

This study was designed to assess the completeness of proxy responses, and the agreement between proxy and case reported information on colorectal screening obtained from a self-administered epidemiologic questionnaire, an outcome that has never been evaluated. Both Nelson et al.[1] and Armstrong et al.[10] have reviewed the literature on the completeness and accuracy of interview data provided by proxy respondents; however, to our knowledge, there is only one study that has assessed self-administered proxy questionnaires.[3]

Item non-response varied greatly and, overall, the level of agreement between case and proxy report was good to excellent. For those variables that did not yield high percentage agreement values, there was generally equal likelihood of proxy over-

TABLE 2
Cell counts and percentage perfect agreement (and 95% CI) between case and proxy report for colonic screening, medical history and medication use

Variable	*Proxy report*** (cell counts)		% perfect agreement (95% CI*)
Case self report (Cell counts)			
Colonic screening			
Ever had hemoccult test			
No	13	7	82 (70, 94)
Yes	0	19	
Reason for hemoccult test			
Diagnostic	9	0	83 (66, 100)
Screening	3	6	
Ever had sigmoidoscopy			
No	11	11	74 (61, 87)
Yes	1	23	
Reason for sigmoidoscopy			
Diagnostic	16	1	83 (68, 98)
Screening	3	3	
Ever had colonoscopy			
No	0	3	92 (85, 100)
Yes	1	48	
Reason for colonoscopy			
Diagnostic	30	2	93 (85, 100)
Screening	1	7	
Medical history			
Ever diagnosed with ulcerative colitis			
No	35	0	92 (83, 100)
Yes	3	1	
Ever diagnosed with irritable bowel syndrome			
No	35	2	95 (88, 100)
Yes	0	1	
Ever diagnosed with diverticular disease			
No	37	1	98 (93, 100)
Yes	0	3	
Ever diagnosed with Crohn's disease			
No	43	0	98 (94, 100)
Yes	1	0	
Ever diagnosed with polyps			
No	14	5	87 (77, 97)
Yes	1	27	

Variable	*Proxy report*** (cell counts)				% perfect agreement (95% CI*)
Case self report (Cell counts)					
Medical history (*cont'd*)					
Age when diagnosed with polyps†					
< 58 years old		5	0	0	95 (85, 100)
58–67 years old		0	5	1	
> 67 years old		0	0	9	
Knowledge of type of polyps					
No			1	0	100 (100, 100)
Yes			0	13	
Ever diagnosed with high cholesterol					
No			32	5	87 (78, 97)
Yes			1	9	
Number of cancers diagnosed					
0	0	1	1	0	78 (65, 89)
1	1	28	1	0	
2	0	4	7	2	
3+	0	0	0	1	
Age of first cancer diagnosis†					
< 58 years old		11	0	1	94 (87, 100)
58–68 years old		0	10	1	
> 68 years old		0	0	12	
Ever had part of large bowel or colon removed					
No			2	2	94 (87, 100)
Yes			1	43	
Age of colon removal†					
< 60 years old		12	0	0	90 (82, 99)
60–69 years old		0	14	2	
> 69 years old		1	1	12	
> 2 surgeries to remove colon					
No			34	0	100 (100, 100)
Yes			0	7	
Ever had gallbladder removed					
No			40	1	96 (91, 100)
Yes			1	9	
Ever had diabetes					
No			45	0	100 (100, 100)
Yes			0	7	

TABLE 2 (*cont'd*)
Cell counts and percentage perfect agreement (and 95% CI) between case and proxy report for colonic screening, medical history and medication use

Variable	*Proxy report*** (cell counts)		% perfect agreement (95% CI*)
Medication and vitamin use			
Ever took calcium pills regularly			
No	29	2	91 (82, 99)
Yes	2	11	
Ever took other laxatives regularly			
No	39	3	91 (83, 99)
Yes	1	1	
Ever took folic acid regularly			
No	39	1	95 (88, 100)
Yes	1	2	
Ever took aspirin regularly			
No	27	4	87 (77, 97)
Yes	2	13	
Ever took acetaminophen regularly			
No	35	3	93 (86, 100)
Yes	0	8	
Medication and vitamin use *(cont'd)*			
Ever took ibuprofen medications regularly			
No	37	4	87 (77, 97)
Yes	2	2	
Ever took multivitamins regularly			
No	30	5	80 (68, 92)
Yes	4	6	
Ever took antacids regularly			
No	33	8	80 (68, 92)
Yes	1	3	
Ever took bulk forming laxatives regularly			
No	36	1	94 (87, 100)
Yes	2	8	

* CI, confidence interval

**Column variable labels (proxy) correspond identically with row labels (case), e.g. in the first item, hemoccult test, there were 13 counts in which both cases and proxies responded "no" and 19 counts in which both responded "yes".

†Tertiles

and under-reporting. Although our sample size was modest, the 95% confidence intervals around agreement estimates are fairly narrow, and therefore our results are easily interpreted.

In line with other studies, we found that proxy item non-response varied by variable and level of detail sought. In previous studies the percentage of missing data reported by proxies ranged from 5% to 50% (for education and smoking details respectively).[11,12] Compared with other studies, the item non-response observed in our study was quite high for several variables, possibly because we used a self-administered questionnaire rather than interview. As well, some of this information was of a fairly detailed nature, e.g., gynecological surgery items, physical activity each decade, and knowledge of a familial adenomatous polyposis diagnosis.

Questionnaires completed by the colon cancer patients had considerably lower item non-response than did the proxy reports. For example, only 6% of the cases did not respond to the fecal occult screening question (versus 27% of the proxies), and 14% of the cases were unable to respond to the familial polyposis question (versus 44% of the proxies).

The one previous study to assess the accuracy of proxy reports obtained using a self-administered questionnaire had findings similar to those of our study, although only medical history, vitamin use, and smoking were evaluated.[3] Herrman[3] found good agreement for diverticulitis and the use of vitamins.

As we did, Wang et al.[13] found that proxy reporting of demographic variables ranged from moderate to good for income and education, was excellent for marital status, and was good for height and weight.[10] We found that the degree of agreement between case and proxy respondent varied depending on the exposure information sought, a finding that is consistent with previous studies.[1,10,14] For number of cancers diagnosed, income and weight, discordant information fell close to the diagonal, indicating partial agreement. Lyon et al.[14] reported that proxy knowledge regarding relatives' alcohol intake (ever/never) throughout different decades of life showed great agreement with case reports, as with our findings. In a review of proxy respondent literature, Nelson et al.[1] found good agreement for serious health events or chronic conditions that would require daily medications, findings that generally reflect our results. Proxy respondents usually provide accurate information for broadly defined variables (e.g., smoking status) whereas detailed exposure infor-

TABLE 3
Cell counts and percentage perfect agreement (and 95% CI) between case and proxy report for alcohol intake, demographic and other variables

Variable	Proxy report** (cell counts)					% perfect agreement (95% CI*)
Case self report (cell counts)						
Alcohol intake						
Any alcohol consumed in 20s						
No				17	5	82 (69, 94)
Yes				2	14	
Any alcohol consumed in 30s						
No				17	5	82 (70, 93)
Yes				3	19	
Any alcohol consumed 50+						
No				15	5	82 (70, 94)
Yes				2	17	
Any alcohol consumption						
No				11	4	86 (76, 98)
Yes				1	21	
Demographic and other variables						
Income						
Under $30,000	11	1	0	0	0	68 (53, 83)
$30,000–$39,999	3	0	3	0	0	
$40,000–$49,999	1	0	7	1	0	
$50,000–$59,999	0	0	2	1	0	
$60,000+	0	0	1	0	7	
Education						
Less than high school	6	0	2	0	0	71 (58, 84)
High school graduate	1	9	1	0	0	
Vocational or technical school	0	0	0	3	0	
Some college or university	0	3	0	7	1	
University degree	1	0	0	2	12	
Ever smoked cigarettes ≥ 3 months						
No				21	0	98 (94, 100)
Yes				1	30	
Ever smoked pipes ≥ 3 months						
No				43	1	94 (88, 100)
Yes				2	8	
Marital Status						
Married	45	0	0	0	0	98 (94, 100)
Separated	0	0	0	0	0	
Divorced	1	0	2	0	0	
Widowed	0	0	0	4	0	
Single	0	0	0	0	2	
Weight† (lbs)						
< 151			13	2	0	78 (66, 90)
151–181			4	6	2	
> 181			0	2	16	

cont'd

mation (e.g., packs per day) is less likely to be accurately reported.[1] We found that for detailed exposures, the percentage agreement did tend to decrease slightly; however, because of insufficient sample size (and large confidence intervals) these data are not presented.

Our findings regarding colonic screening (ever/never) demonstrate excellent case-proxy agreement on reports of both hemoccult tests and colonoscopy, and good agreement on sigmoidoscopy. Knowledge of whether each of these procedures was for screening or diagnostic reasons was also reported with excellent agreement between proxy and case report. The type of polyps diagnosed (e.g., benign, adenomatous) was reported by proxies with perfect agreement.

Previous studies suggest that siblings may be the best respondents for questions on early life events or family medical history, and spouses and offspring may be best for adult life events.[11] Further research evaluating the accuracy and completeness of colonic screening information provided by proxies would benefit from larger samples, as this would allow for stratification by variables of interest (e.g., relationship of proxy to subject, sex, and age). Furthermore, the wide confidence intervals observed for some variables limit the interpretation of our findings, and larger studies are needed to evaluate proxy reports for variables not yet studied well, such as colonic screening.

When interpreting our findings, it is important to consider that participating proxies may have a greater health interest and be better informed than non-participants. Therefore, our findings may overestimate the accuracy of proxy reports. As well, the generalizability of this study to proxy reports obtained for deceased cases (rather than living cases) is of importance. Proxies in this study were approached within a year of the case diagnosis, a similar time frame to that found in typical case-control studies using true proxies. As a result, it is not expected that the accuracy of proxy recall would be any lower than in other, similarly conducted case-control studies.

Epidemiologic studies of cancers with a poor survival rate (e.g., colorectal cancer)

TABLE 3 (*cont'd*)
Cell counts and percentage perfect agreement (and 95% CI) between case and proxy report for alcohol intake, demographic and other variables

Variable	Proxy report** (cell counts)			% perfect agreement (95% CI*)
Height†				
< 64 inches	12	2	1	81 (72, 92)
64–68 inches	3	11	2	
> 68 inches	0	2	21	

* CI, confidence interval

**Column variable labels (proxy) correspond identically with row labels (case), e.g., in the first item, alcohol consumed in the 20s, there were 17 counts in which both cases and proxies responded "no" and 14 counts in which both responded "yes", 5 counts where proxy responded "yes" and case responded "no", and 2 counts where case responded "yes" and proxy responded "no".

† Tertiles

TABLE 4
Cell counts and percentage perfect agreement (and 95% CI) between case and proxy report for reproductive history variables

Variable	Proxy report** (cell counts)			% perfect agreement (95% CI*)
Case self report (Cell counts)				
Ever took hormone replacement				
No		11	1	95 (86, 100)
Yes		0	9	
Menstruated in last 12 months (menopausal status)				
No		23	0	92 (82, 100)
Yes		2	1	
Ever pregnant				
No		3	0	100 (100, 100)
Yes		0	27	
Number of pregnancies†				
< 3	9	1	0	84 (70, 98)
3	2	7	0	
> 3	0	1	5	
Age of first live birth†				
< 21 years old	8	0	1	92 (81, 100)
21–24 years old	0	6	0	
> 24 years old	0	1	8	
Hysterectomy				
No		9	1	91 (74, 108)
Yes		0	1	

* CI, confidence interval

**Column variable labels (proxy) correspond identically with row labels (case), e.g. in the first item, hormone replacement, there were 11 counts in which both cases and proxies responded "no" and 9 counts in which both responded "yes"

†Tertiles

must often rely on proxy respondents to complete risk factor questionnaires. The present study provides evidence for the usefulness of proxy data on such variables as medical history and colonic screening, reproductive data, vitamin use, and current weight, whereas variables such as physical activity and oral contraceptive use are not well reported by proxies. This study provides an important addition to the existing literature in that it demonstrates the accuracy of proxy-reported broadly defined colonic screening variables, and the usefulness of mailed, self-administered proxy questionnaires for the ascertainment of epidemiologic data.

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Regional comparisons of inpatient and outpatient patterns of cerebrovascular disease diagnosis in the province of Alberta

Nikolaos Yiannakoulias, Lawrence W Svenson, Michael D Hill, Donald P Schopflocher, Robert C James, Andreas T Wielgosz and Thomas W Noseworthy

Abstract

The diagnosis of cerebrovascular disease (CBVD) from administrative data has been critically examined by epidemiologists in recent years. Much of the existing literature suggests that hospital discharge diagnoses based on ICD-9-CM codes are an unreliable source of information for determining a diagnosis of stroke, particularly when four- and five-digit codes are used. We examined how diagnoses for CBVD in hospital inpatient and outpatient facilities vary between rural and urban areas and among the 16 administrative health regions. Our analysis revealed differences in diagnostic patterns between the two sources of data, differences between rural and urban areas, and variation across most of the regions. Geographic variation in health service utilization, diagnostic practices, specialty of the physician making the diagnosis, and disease burden may explain our findings. Our results suggest that the diagnosis of patients attending rural facilities are either coded differently (and less precisely) than those of urban residents or are coded more precisely only after the patients attend urban facilities. Regional differences in coding practices show that any CBVD surveillance system based on administrative data requires a large-scale (in this case, province-wide) and person-oriented approach.

***Key words:**, administrative data; cerebrovascular disease; epidemiology; stroke*

Introduction

Cerebrovascular disease (CBVD) is the third leading cause of death in Canada, behind only heart disease and cancer.[1] Although its incidence has been declining in recent years, an ageing population means that the absolute number of cases and cost of treatment are likely to rise.[2]

Surveillance is an important component of any strategy to address the future health impacts of CBVD and, more specifically, stroke.[3,4] A central characteristic of surveillance is the ongoing, systematic collection, analysis and dissemination of population-based data and information.[5,6] Rather than focusing on a group at particular risk, public health surveillance monitors the health of the population as a whole. Effective surveillance systems must balance accuracy and completeness while remaining both representative and comprehensive enough to make meaningful statements about disease at large.[7]

In Canada, an increasingly available source of surveillance information includes administrative health care databases of inpatient, outpatient and physician billing data. Administrative data can be a cost-effective, timely and generalizable resource for the surveillance of CBVD and other health outcomes.[8] In most administrative data systems, case definitions are based on ICD-9-CM (International Classification of Diseases, 9th Revision, Clinical Modification) coding schemes.[9] However, there is considerable variability in the methods and accuracy of stroke diagnosis when ICD-9-CM codes are used.[10] Hospital discharge data may overestimate stroke incidence.[11,12] Validation studies using medical records also report that ischemic cerebrovascular disease is not coded reliably in administrative data.[13,14]

In addition to identifying the overall incidence and/or prevalence of a disease in a given jurisdiction, surveillance systems are also concerned with regional (geographic) variation. Geographic differences in stroke incidence and mortality have been noted in a number of studies.[15,16] However, given the uncertainty about the quality of stroke diagnoses in administrative data and evidence that diagnostic coding differs regionally,[17] it is unclear whether these variations are confounded by misclassification, leading to geographic variations in diagnostic patterns independent of true epidemiologic differences.

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Regional variation in medical coding practices combined with the need for specific case definitions that separate CBVD into logical subsets of illness (e.g., acute stroke, transient ischemic attack, late effects of stroke) present a seemingly intractable problem for CBVD surveillance that uses administrative data. On the one hand, case definitions must be detailed enough to be useful for epidemiologic and surveillance purposes. On the other hand, there may be regional variation in the accuracy of coding in general, and as diagnoses become more specific, variations in coding accuracy may increasingly confuse the results. More research is required that investigates how the coding varies regionally and to what degree facilities differ in their methods of coding disease.

It is possible that the use of multiple administrative data sources may provide more accurate and robust estimates of disease impacts. Despite the important literature on the quality of Canadian hospital discharge data,[18,19] little work has been done to evaluate CBVD diagnoses from ambulatory or physician claims data. Outpatient data may improve estimates of incidence and/or prevalence since they represent a different part of the health service system, with potentially different information collection practices. For example, people who die in or are discharged from emergency departments will not appear in hospital inpatient data but will appear in the outpatient system.

The goal of this study was to describe and evaluate regional differences in CBVD diagnostic coding subgroups in hospital inpatient and outpatient data. In addition to describing the distribution of CBVD ICD-9 coding collected from inpatient and outpatient administrative data sources, we make geographic comparisons between the pattern of coding in inpatient and outpatient data. This research is important in helping to establish a preliminary framework for the use of large-scale administrative data in the geographic surveillance of cerebrovascular disease. By outlining the limitations of administrative data, we improve our ability to employ it effectively. Our findings will also help characterize the interaction between facility location, CBVD and diagnostic coding variability, and will indicate the degree to which administrative data can capture the underlying characteristics of illness across Alberta.

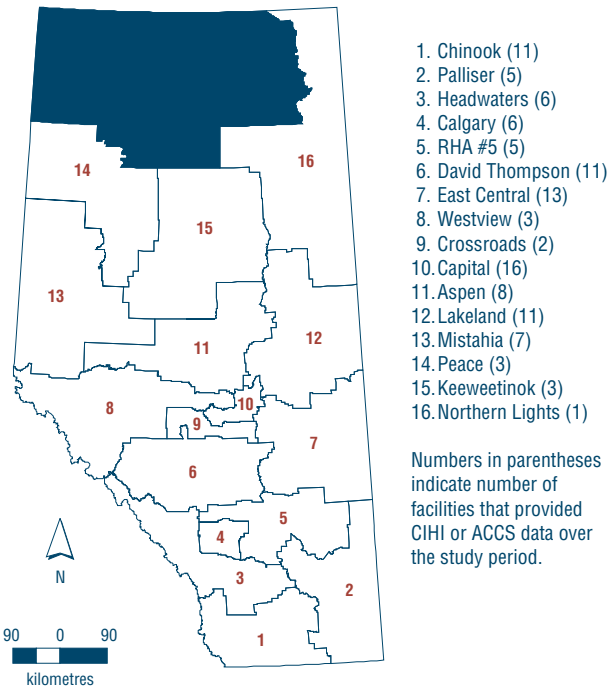
Methods

All residents of Alberta are eligible for coverage under a publicly funded health care system. Very few residents opt out of the system, and therefore the registry captures the vast majority of the population of Alberta (roughly three million people). Each resident covered by the plan has a personal health number, which can be used as a link to a variety of data sources. Non-residents who receive services in Alberta are not tracked through the registry system but are still recorded in the health data systems.

We used two administrative data systems to collect case information. Inpatient data were acquired from a nationally standardized collection of hospital morbidity data, from the Canadian Institute for Health Information (CIHI). Our other source, the Ambulatory Care Classification System (ACCS), includes data from hospital outpatient facilities. Most of these data are from emergency departments, the remainder coming from day surgeries, outpatient treatment programs/clinics and other facilities that do not involve overnight stay. Alberta has collected and maintained ACCS data since 1997/1998 and currently remains one of the few jurisdictions in North America to maintain a comprehensive digital record of outpatient services. In most cases, inpatient and outpatient records are coded by the same staff of medical records coders.

Data were acquired for the 1999/2000 fiscal year and were evaluated across 16 health regions as well as rural and urban areas in the province of Alberta (Figure 1). Over the study period, 69 rural and 44 urban facilities contributed records to the ACCS and/or CIHI data systems. Although Alberta is divided into 17 health regions, the Northwestern Health Authority did not have complete outpatient data and was therefore excluded from this study. For CIHI data there are up to 16 diagnostic fields; for ACCS data there are up to six diagnostic fields. Our analysis covered all records coded as cerebrovascular disease (430.x to 438.x) in any diagnostic field within inpatient and outpatient facilities. Therefore our data were transaction based, not per-

FIGURE 1
Regional health authorities in Alberta, 1998 boundaries



son based. A transaction-based analysis was required in order to observe the pattern of diagnostic coding made in different health regions. Person-based analysis would approximate disease frequencies, which would obscure the variation in coding practices across regions. Since our goal is not to assess the disease frequency across regions but to identify how coding varies among regions and between inpatient and outpatient data systems, a transaction-based approach was necessary.

For analysis, records were characterized by two different geographic levels: health region and rural/urban. Rural/urban was defined according to the six-digit postal code of the facility in which the service took place: a service facility was classified as "rural" if the second digit of its postal code was a "0" and classified as urban in all other cases. This definition is used by Statistics Canada.[20] The matrix of CBVD subgroup diagnostic codes by region was examined using multivariate ordination techniques.[21,22] Specifically, the matrix was represented as a biplot in the space of the first two principal components. Groupings were formed by examining the proximity of points representing regions.

Results

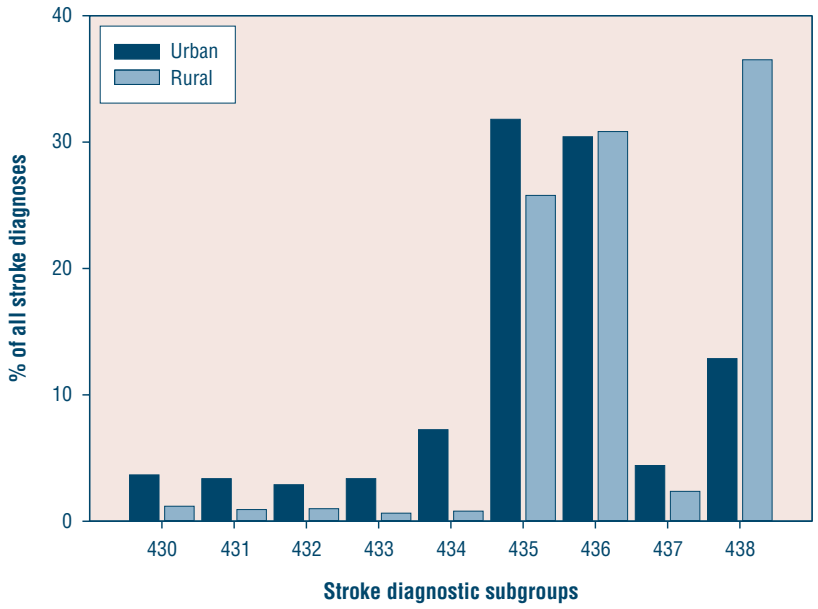
Diagnoses in inpatient and outpatient facilities

When reclassified into the three-digit ICD-9-CM subgroups, CBVD diagnostic codes in inpatient centres differ noticeably from codes in outpatient centres (Table 1). This is not surprising, since inpatient and outpatient facilities serve the public differently. The difference is most noticeable in the 435.x to 438.x diagnostic groups. The greatest difference is in subgroup 436, which makes up nearly 25% of all outpatient codes for CBVD but roughly 14% of inpatient services. Using a specialty code available in physician billing data, we were able to estimate that only 9% of emergency department diagnoses (which make up the majority of outpatient records) of CBVD were made by neurologists. Because of a lack of data availability, similar conclusions could not be made about inpatient data, although it is likely that neurologists determine a larger proportion of diagnoses for admitted hospital patients.

TABLE 1
Diagnostic subgroups for cerebrovascular disease (% of all stroke diagnoses)

ICD9-CM	Diagnosis	Inpatient	Outpatient
430.x	Subarachnoid hemorrhage	2.32	5.38
431.x	Intracerebral hemorrhage	4.68	6.21
432.x	Other and unspecified intracranial hemorrhage	3.00	3.56
433.x	Occlusion and stenosis of precerebral arteries	10.46	2.70
434.x	Occlusion of cerebral arteries	17.05	17.86
435.x	Transient cerebral ischemia	13.31	21.70
436	Acute, but ill-defined cerebrovascular disease	13.91	24.60
437.x	Other and ill-defined cerebrovascular disease	11.18	3.47
438.x	Late effects of cerebrovascular disease	24.10	14.50

FIGURE 2
Rural and urban outpatient diagnostic groupings for cerebrovascular disease, 1999/2000

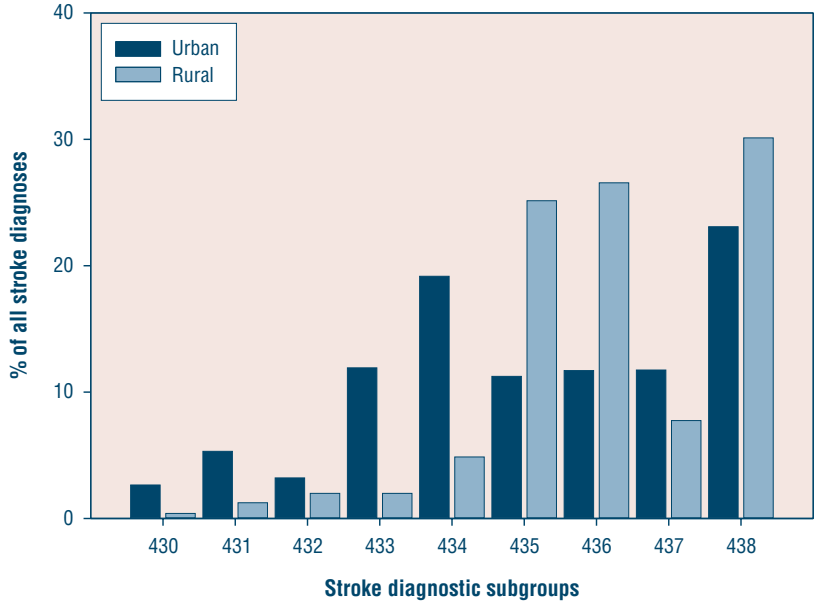


Rural versus urban

The distribution of diagnostic codes differs between rural and urban facilities for both outpatient (Figure 2) and inpatient (Figure 3) service centres. In outpatient service facilities, the biggest single urban/rural difference is in the 438.x diagnostic group, which represents a much greater proportion of all stroke diagnoses in rural than in urban facilities. For most other diagnostic categories, urban facilities make up a larger proportion of diagnoses. For 435.x and 436, the frequency of coding is similar for urban and rural areas. Inpatient facilities show considerable urban/rural contrast for codes 435.x and 436, and less for 438.x.

When broken down into the specific diagnostic codes available in administrative records, inpatient data continue to demonstrate a considerable urban/rural contrast. Rural areas code 436 (26.6%), and 435.9 (24.2%) (unspecified transient cerebral

FIGURE 3
Rural and urban inpatient diagnostic groupings for cerebrovascular disease, 1999/2000



ischemia) considerably more often than urban areas (11.7% and 9.9% respectively). The frequencies of specific codes have a wider range among urban facilities than rural facilities: of the 58 types of diagnosis that were made in Alberta inpatient facilities, 39 were reported with greater frequency in urban areas. In the outpatient data, the two most common codes (436 and 435.9) are used with similar frequency in rural (21.0%, 16.9%) and urban (23.8%, 16.7%) areas. The biggest difference in the frequency of outpatient diagnoses between urban and rural areas is for 438.9 (unspecified late effects of cerebrovascular disease): 15.1% coded in rural areas and 3.8% coded in urban areas. However, as with inpatient facilities, diagnoses coded in urban facilities are distributed more widely across all diagnoses coded: of the 57 types of diagnoses that were made in Alberta outpatient facilities, 38 were reported with greater frequency in urban areas.

Regional differences

The matrices of CBVD subgroup diagnostic codes by region are shown as profiles in Figures 4a-e and 5a-d. With the exception of 4e (which is best understood as a residual grouping), the success of this strategy is visible in the graphs; regions with similar diagnostic profiles are generally grouped together. Regional differences in diagnostic codes within the CBVD subgroups are most noticeable in outpatient data (Figures 4a-4e). Three diagnostic subgroups make up a significant majority of all CBVD coding in most regions: 435.x, 436 and 438.x. In regions 6, 11 and 15, a majority of records are coded as 438.x (Figure 4a). In regions 13 and 14, 436 makes up the majority of diagnostic codes (Figure 4b). In regions 1, 4, 7 and 9 (Figure 4c), 435.x and 436 share a similar proportion of the overall CBVD coding, and regions 2, 3, 5, 8 and 12 see similar proportions of records coded between sub-groups 435.x, 436 and 438.x (Figure 4d). Regions 10 and 16 possess diagnostic patterns notably different from the other regions (Figure 4e). For region 10, 434.x is coded in over 30% of the cerebrovascular disease records, significantly more often than in the other regions. In region 16, 430.x is coded frequently, although the total number of diagnoses in this region is small. The remaining regions show similar patterns: 436 and 438.x are most commonly coded, and 430.x to 434.x are coded considerably less frequently.

The regional variations in coding among inpatient data can be classified into two main groups (Figures 5a-5d). First, regions 10 and 4 exhibit very similar patterns of coding, characterized by a more uniform distribution and a smaller proportion of 436 diagnoses (Figure 5a). The most commonly coded subgroups in these two regions are 434.x and 438.x. In most of the remaining regions, the most common codes are 435.x, 436 and 438.x, although the relative proportions among these three diagnoses differ. Regions 1, 2, 5 and 16 do not conform to either of these patterns in particular, although 435.x, 436 and 438.x are commonly coded in these regions (Figure 5d). In this case, diagnostic codes are divided more evenly between the subgroups in general.

Discussion

There are quantifiable differences between regions and between rural and urban areas in the frequency of CBVD coding by the three-digit diagnostic subgroupings. Furthermore, these differences in coding profiles vary between the inpatient and outpatient data. The differences may be explained by genuine differences in the burden and/or epidemiology of CBVD, by regional differences in medical coding practices or differences in the methods of diagnosis, or they may reflect geographic differences in the organization of stroke care. The data may also indicate that inpatient and outpatient facilities are utilized differently across the province. Thus, our results merely provide a description of regional differences in coding and cannot be used to explain the causes of these differences. Our results do, however, reveal a number of issues that researchers should consider when using administrative data to analyze regional differences in CBVD frequency.

Urban facilities code a wider range of diagnoses than rural facilities in the inpatient and outpatient data systems. Overall, urban/rural differences in patterns of diagnostic coding are greater among inpatient data. In the inpatient setting, rural facilities code over 25% of their CBVD records as 436, whereas urban areas code roughly 12% of their records as 436. For outpatient

FIGURE 4a-e
Outpatient cerebrovascular disease diagnostic groups by region, 1999/2000

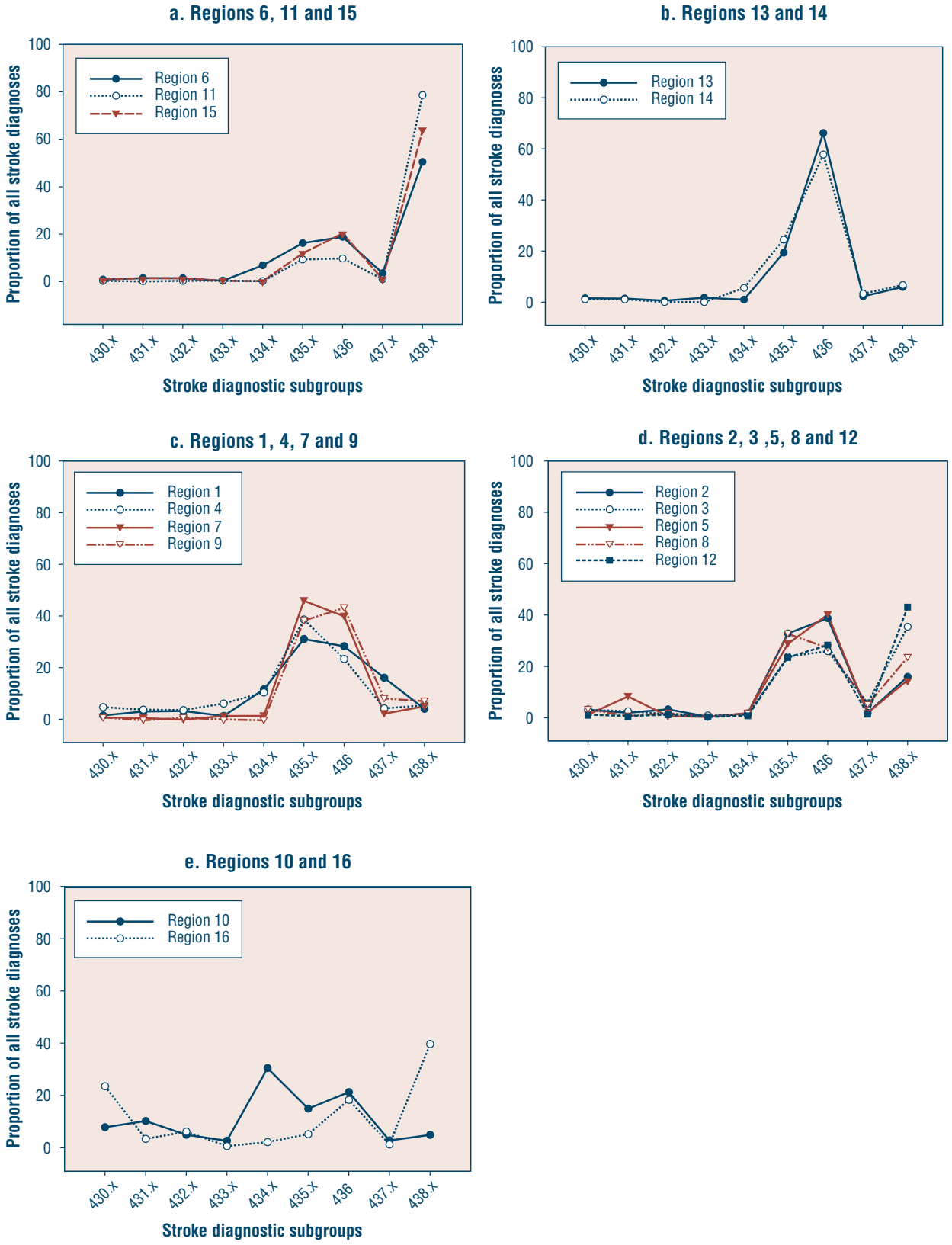
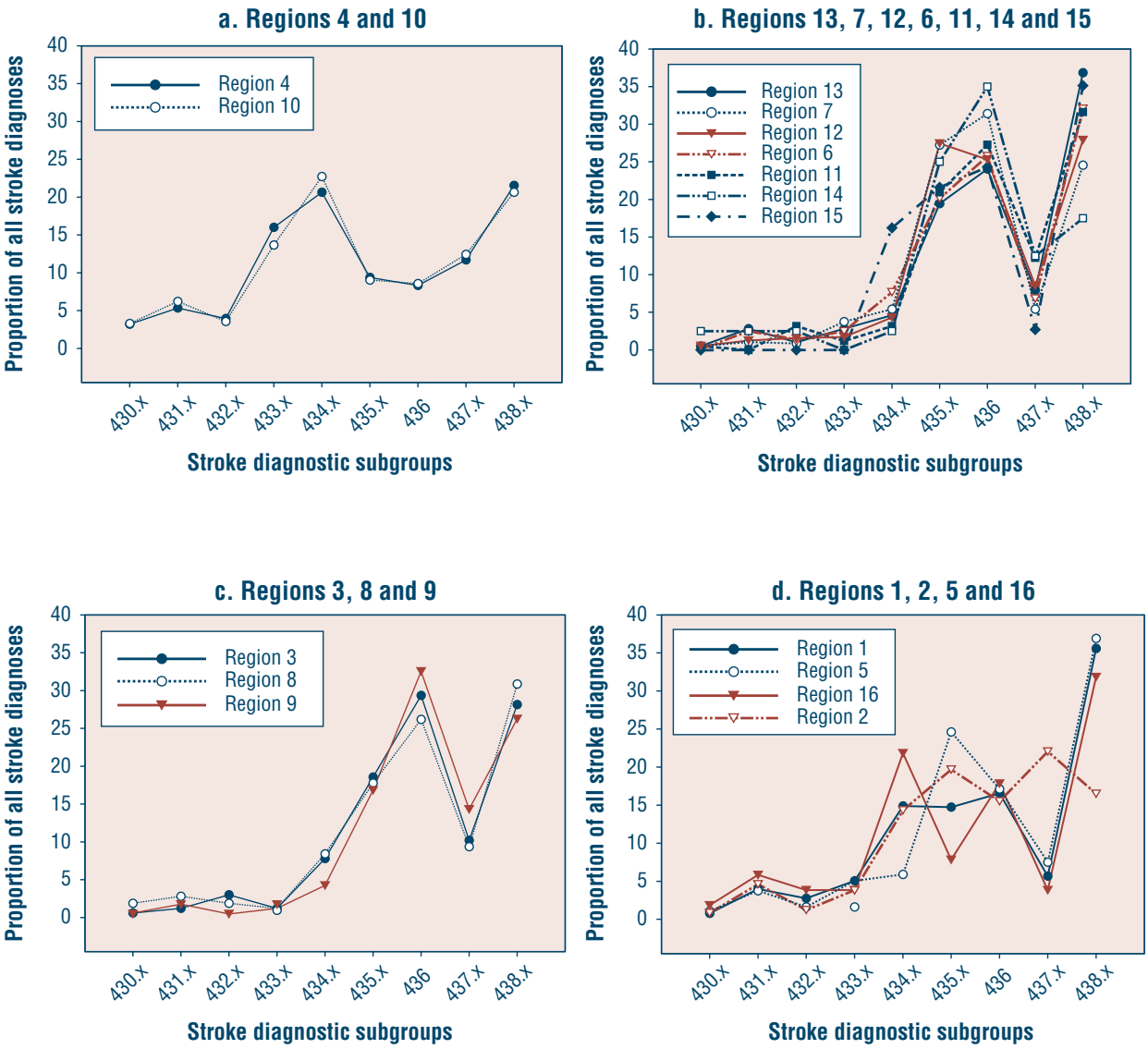


FIGURE 5a-d
Inpatient cerebrovascular disease diagnostic groups by region, 1999/2000



data, a very similar proportion of diagnoses are coded as 436 in rural and urban areas (~30%). Another frequently coded diagnosis, 435.9, also shows a similar and notable urban/rural contrast in inpatient facilities, though differing little in outpatient facilities. Indeed, the pattern of diagnostic codes 436 and 435.9 demonstrates a similarity between diagnostic patterns in rural inpatient records and outpatient records as a whole.

There are two distinct regional patterns visible in the inpatient data, which re-illustrate the urban/rural contrasts already noted. Inpatient facilities in regions 10 and 4 (which include Edmonton and Calgary respectively) code the CBVD subgroups with virtually identical frequency, the largest proportions of diagnoses being coded as 433.x, 434.x and 438.x. The vast majority of specialists and neurologists are located in these two urban centres. If, as suggested earlier, neurologists determine a larger proportion of diagnoses within hospital inpatient data, then this pattern may reflect a greater degree of consistency and diagnostic certainty among neurologists. The similarities between Calgary and Edmonton may reflect similar disease frequency, coding standards, or a combination of both factors.

Among outpatient data, the regional variations are noteworthy. The magnitude of variation within the patterns suggests that the three most common diagnostic codes in the majority of regions (435.x, 436 and 438.x) may represent similar classification phenomena to physicians and/or medical coders. Evidence for this conclusion is twofold. First, the magnitude of variation is unlikely to be represented by real differences of disease in the population. For ex-

ample, in regions 6, 11 and 15, over 50% of the diagnoses for CBVD are coded as 438.x. In regions 1, 4, 7, 9, 10, 13 and 14, less than 10% of records have the same diagnosis. It seems implausible that such a large magnitude of variation would be due to true regional differences in epidemiology. Second, regions with similar demographic characteristics and similar numbers of neurologists nonetheless exhibit markedly different patterns of diagnosis. Regions 4 and 10 are urban areas that have similar populations in terms of demographic features and health. Nevertheless, they differ greatly in how frequently 434.x is coded. Over 30% of outpatient records for CBVD are coded as 434.x in region 10; in region 4, less than 12% of the records are similarly coded.

This analysis was transaction based, and therefore the geographic component was defined by the facility a patient visited and not his or her place of residence. This was an important detail of our analysis since it allowed us to observe the trends in coding (separate from trends in disease frequency) and identify the degree to which coding differs regionally. However, any tendency for rural living people to specifically seek service at urban inpatient and/or outpatient facilities (i.e., seek treatment at facilities outside their region of residence) influences our findings. Rural records may frequently represent initial contacts that are followed up in urban facilities, where more precise codes will be used. This is an important question for future research – how often do rural residents receive more definitive and/or accurate diagnoses in non-local facilities?

Estimates of disease frequency may also be complicated by multiple visits to different facilities; rural people may receive non-specific diagnoses in a rural facility before they are transferred to an urban facility, where a more specific diagnostic code is obtained. When determining the disease status of a given individual, one would need to decide which of the two codes is more appropriate. Nevertheless, our findings do suggest that obtaining information exclusively from medical records in rurally located facilities may not be sufficient for surveillance or research purposes. Regional differences in the availability of specialized diagnostic equipment and necessary expertise may hide real differences in epidemiology. This may be because rural living people tend to seek services in urban areas, or it may reflect distinctly different coding practices among rural facilities. Whatever the reason, facilities in rural health regions have widely different patterns of CBVD coding, in many cases in both the hospital inpatient and outpatient settings. This could have an effect on geographic estimates of CBVD frequency in general, even when case definitions are person based.

Our findings also illustrate the importance of person-oriented data in health surveillance and research, particularly when regional comparisons are being made. Cross-sectional data may be a geographically and otherwise biased representation of CBVD in which rural residents receive a disproportionately large number of non-specific diagnostic codes. Our findings may indicate that rural residents receive a non-specific diagnosis in rural areas, and that more specific codes are received only after transfer to an urban facility. As such, even though a first encounter may have been in a rural facility, the diagnostic codes associated with an encounter at the urban facility may be better suited for defining the characteristics of the individual's illness. Tracking the complete diagnostic and service history of individuals may help to mitigate some of this bias. For cases in which people receive different diagnoses from different facilities over time, extended information can be collected and analyzed as a whole to obtain a more precise measure of illness. This could also offset the uncertainty associated with ICD-9 codes used in administrative data. Although location of residence may still influence people's utilization habits and ultimately the patterns of CBVD, person-oriented administrative data surveillance offers the best option for addressing these problems related to administrative data.

Conclusions

There is some evidence to suggest that hospital inpatient data collected from urban areas offers the most consistent CBVD diagnostic coding in Alberta's administrative health data system. This may be a result of the availability of diagnostic equipment and specialists, or the training and expertise of medical coders, or a combination of these and other factors. This does not eliminate the possibility of confounding or inaccuracy in the diagnostic coding, but it does suggest that the error is similar among large urban areas, and therefore comparisons based on inpatient data are probably meaningful. The inconsistency of diagnoses made in rural areas suggests that a) some geographic patterns obtained through the administrative data system in CBVD may still be confounded by variations in coding (despite the similarities of Edmonton and Calgary) and b) estimates of disease incidence will be increasingly obscured with the use of increasingly detailed ICD-9 diagnostic codes.

Our results also suggest that either rural residents receive distinctly different (and in general, less specific) diagnostic codes than urban residents, or rural residents frequently attend urban facilities for diagnosis. If the former, then further research must be done to assess whether this differential coding is reflective of differential treatment. If the latter, then research must be undertaken to evaluate the effect that commuting to urban areas for diagnosis and treatment may have on the health of rural residents. In addition, validation work is necessary to confirm the existence of diagnostic bias from region to region and to characterize its type and direction. Geographic differences in the distribution of diagnoses may be explained by regionally specific coding practices, regional differences in disease burden, or a tendency for people in some regions to use local service centres selectively. Finally, further work is required that tracks utilization across the system as a whole and follows patients' utilization habits across geographic area, time and type of service.

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Collection and retention of demographic, medical, and occupational information in northeastern Ontario workplaces

Nancy Lightfoot, Jennifer Dumont, Michael Conlon, Rachelle Arbour-Gagnon, Tim Rico, Sharon Duhamel and Randy Bissett

Abstract

This study determined whether workplaces in northeastern Ontario currently collect and retain demographic information, medical history, work history, and information on occupational exposure. Surveys were mailed to 434 northeastern Ontario workplaces with 50 or more employees, and a telephone follow-up was conducted. The response rate was 42.6% (185/434). Over 97% of workplaces reported that they always collect surnames and first names of employees, 13.5% reported collecting maiden names (and 70.8% never collect maiden names), 85.4% collect date of birth, 55.7% next of kin, 97.8% current address, 21.6% medical history, and 31.9% collect the health insurance number. Job titles were routinely recorded by 79.5%. Start and end dates for each job were always recorded by 68.1%, and 70.3% reported that they always note the area of work. Overall, 64.9% of workplaces collected previous place of employment. For 72.1%, legislation influenced the amount of information collected on current records. Thirteen percent routinely recorded smoking history on occupational health records, and 25.9% undertook exposure surveillance. This type of information can assist in planning occupational epidemiological studies.

Key words: *epidemiology; occupational health, surveillance*

Introduction

According to the founding statement issued in February 2001 by the newly formed Canadian Association for Research on Work and Health, the majority of adult life is devoted to work-related issues, and disabilities and diseases associated with work activities can affect both individuals and Canadian society.[1] The founding statement also indicates that Health Canada estimates the annual cost of productive time from short- and long-term disability and premature mortality to exceed $44 billion[2] and suggests that about half of this amount is directly related to diseases and injuries that are work associated.[1]

It is important for Canadian businesses to be aware of health and safety legislation; issues surrounding the collection and retention of information about employee demographic, health, and safety; and occupational exposures relevant to their particular workplaces. This type of information can prove valuable in the prevention and/or reduction of diseases and injuries, for compensation purposes, and to assist legislators and policy makers in establishing workplace exposure standards and guidelines. Although periodic retrospective review of health and safety statistics by a specific workplace for compliance purposes tends to be emphasized, prevention of occupational diseases and injuries, or at least reduction and minimization of their occurrence in workplaces, should be of paramount importance. Such shifts in focus can result in benefits at a personal and familial level as well as in terms of the available work force, benefits reduction, and compensation reduction.

Occupational epidemiological teams may be asked to undertake various types of workplace-related applied research studies, such as studies of a surveillance or etiological nature. Although the teams are capable of collecting original data, quite often their capabilities will depend largely on the quality of data collected previously by the workplace, particularly if the study includes historical information over a long period of time.

This study was modeled closely after studies conducted by Rushton and Betts in the United Kingdom and subsequently in the European Economic Community.[3–5] The objectives of this voluntary, cross-sectional study were to 1) determine what information on demographic factors, medical history, work history, and occupational health is collected by northeastern Ontario workplaces with 50 or more employees, 2) ascertain how long the information is retained, and 3) ultimately make recommendations and suggest guidelines governing the collection and retention of such information in northeastern Ontario.

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Methods

The catchment area for this northeastern Ontario study consisted of the following nine census divisions: Algoma, Cochrane, Timiskaming, Nipissing, Parry Sound, Muskoka, Manitoulin, Sudbury District, and Sudbury Region. The study team decided to focus on businesses with 50 or more employees in order to avoid interaction with very small workplaces that are unlikely and unable to collect much more than very basic demographic information.

The questionnaire for the study was based on a copyrighted questionnaire developed by Rushton and Betts for use in a survey of industries in the European Economic Community; this was based on a similar survey that they had conducted in the United Kingdom.[3–5] Rushton provided copies of sections used in the European survey. Very slight modifications were made where terminology differed. The questionnaire contained three major sections: personnel records, occupational hygiene and exposure records, and occupational health and medical records, and took about 20 to 30 minutes to complete.

The short questionnaire, available in both English and French, was produced in booklet form. It was mailed to chief executive officers or directors of northeastern Ontario businesses for distribution to 434 workplaces with 50 or more employees. The names and addresses of the businesses were purchased from the Canadian Business Directory.[6]

In this study, workplaces with 50 or more employees were selected for study based on a desire to survey workplaces of reasonable size that would have joint health and safety committees. In Ontario, joint health and safety committees are required

- in workplaces that regularly employ 20 or more workers
- for construction projects, anticipated to last three or more months, that regularly employ 20 or more workers, or
- for workplaces, other than construction projects, for which a regulation about a designated substance applies, even if fewer than 20 workers are regularly employed
- any workplace where an order has been issued under section 33 of the Act (for "toxic substances)" even if fewer than 20 workers are regularly employed
- any workplace or construction project that has been ordered by the Minister of Labour to form a committee[7,8]

Occasionally an alternative to a committee is permitted, if it provides comparable benefits for worker health and safety.[7,8] Under special conditions, The Minister of Labour may also permit a single committee to be established for more than one workplace.[7,8]

Directions for completion by the most appropriate person(s) were included. Workplaces were free to select the most relevant person(s) to complete the three sections of the questionnaire, and job titles were ascertained for people completing each section. Stamped return envelopes were provided.

In order for the interviewers to prepare and cope with the number of questionnaires required for mailing, approximately 50 questionnaires were mailed out per week between November 23, 1999, and February 1, 2000. Telephone follow-up was conducted about every two weeks until early September 2000. Identification numbers were recorded on questionnaires for follow-up purposes, but potential study participants were assured that their individual responses were strictly confidential, reviewed only by study staff, and were ultimately shredded, and that the study results would be reported for group information only.

Returned questionnaires were coded, the data entered into the computer, and verified. After data quality assessment, simple frequencies, percentages, cross-tabulations, and *t* tests were performed in SPSS for Windows version 9.0.[9]

Results

The response rates for the study are shown in Table 1. The study response rate was 42.6%. The study refusal rate – the proportion of workplaces that indicated their refusal to take part in the study – was 34.1%. If refusals, unreturned questionnaires, questionnaires lost in the mail, and questionnaires returned blank are also considered refusals, the refusal rate was 57.1%.

TABLE 1
Study response rates

Number of questionnaires mailed to businesses	534
Number of questionnaires returned	185
Number of businesses that refused to participate	148
Number of questionnaires returned that were lost in the mail	29
Number of businesses that no longer exist or were amalgamated	100
Number of businesses that did not return the questionnaire or that returned it unmarked	71
Response rate for eligible businesses: 185/434	42.6%
Refusal rate: 148/434	34.1%
Refusal rate if refusals, questionnaires not returned, questionnaires lost in the mail, and questionnaires returned unmarked are included: 248/434	57.1%

The median number of employees reported by responding workplaces was 120, and the range was from 50 to 11,000.

The types of industry sectors represented in the study appear in Table 2. The majority (54.1%) considered themselves represented by the "other" or miscellaneous industry sector category. The remaining industrial sectors represented varied, and all sectors listed in the questionnaire were represented. Following the "other" category, transportation and communication was the next largest percentage of workplaces (8.6%), the distribution, hotels and catering, and repairs sector followed (8.1%), and other manufacturing industries were listed by 7.6% of the businesses.

TABLE 2
Distribution of industry sectors represented in the study (number of workplaces = 185)

Sector	Frequency	Percentage
Agriculture, forestry, and fishing	7	3.8
Energy and water	5	2.7
Extraction of minerals and ores other than fuels, manufacture of metals, mineral	5	2.7
Products and chemicals	1	0.5
Metal goods, engineering and vehicle industries	9	4.9
Other manufacturing industries	14	7.6
Construction	7	3.8
Distribution, hotels and catering, repairs	15	8.1
Transport and communication	16	8.6
Banking, finance, business services and leasing	6	3.2
Other (e.g., medical, educational, etc.)	100	54.1
TOTAL	185	100.0

TABLE 3
Demographic information routinely collected on recruitment of employees (number of workplaces = 185)

Information	Percentage*				
	Always	Usually	Sometimes	Never	Missing
Surname(s)	97.8	2.2	0	0	–
Maiden name(s)	13.5	2.7	13.0	70.8	–
First name(s)	98.9	1.1	0	0	–
Sex	75.1	4.9	3.2	16.8	–
Current address	97.8	1.6	0.5	0	–
Postal code	97.8	1.6	0.5	0	–
Place of birth	15.7	0.5	4.9	78.9	–
Nationality	6.5	2.2	4.3	87.0	–
Ethnicity	3.8	0.5	4.9	90.8	–
Date of birth	85.4	4.9	0.5	9.2	–
Marital status	61.6	10.3	6.5	21.6	–
Next of kin	55.7	10.3	10.8	23.2	–
Number of children	28.1	8.1	18.9	44.9	–
Health insurance number	31.9	3.8	4.9	59.5	–
Staff identity number	81.6	8.1	4.3	3.2	2.7
Job titles	79.5	2.2	1.6	2.7	14.1
Start and finish date for each job	68.1	9.7	8.6	2.7	10.8
Location (i.e. site/plant)	62.7	5.9	5.9	3.2	22.2
Section/work area/department/ work group	70.3	7.6	6.5	2.2	13.5
Salary level(s)/grade(s)	86.5	6.5	1.6	1.6	3.8

*Numbers in tables may not always add to 100 because of rounding.

A. Personnel or human resource information

The first section of the questionnaire inquired about personnel or human resources information collected and noted that records could be held in more than one location. Multiple response analysis revealed that 75.1% routinely hold current employee records in personnel or human resource areas, 34.6% reported that they hold them in salaries, wages, or finance areas, and 17.8% hold them in a wide variety of other areas.

Current employee records are held on paper and computer by 65.2%, on paper only by 36.4%, on computer only by 1.6%, and by means of other types of storage by 1.6%. The respondents were asked to check all methods that applied to their situation.

The demographic information routinely collected on recruitment of current employees is listed in Table 3. In the case of information always collected the highest percentages recorded were for first name(s), and surname(s), current address and postal code, followed by date of birth and sex. The categories for which demographic information was never collected were ethnicity and nationality, followed by place of birth and maiden name(s).

The demographic information in Table 3 is updated occasionally by 36.4% of workplaces, updated yearly by 19.6%, never updated by 4.3%, and updated monthly by 1.6%. Responses could include more than one category. The majority (42.4%) update this information on the basis of other criteria (e.g., as change requires, as provided by staff).

The distribution of some routinely collected occupational information for current staff is also provided in Table 3. The following occupational information was always collected by more than 75% of the responding workplaces (in order from highest to lowest): salary level(s) or grade(s), staff identity number, and job titles. Most workplaces (70.3%) always note section, work area, work department, or work group; 68.1% always record start and finish dates for each job; and 62.7% always collect location (i.e., site or plant) worked. Previ-

ous places of employment were noted by 64.9% of businesses.

Multiple response analysis of the various factors that may have influenced the amount of information collected on current employee records shows that storage costs are a factor for 75.4% of respondents, payroll administration for 73.2%, legislation for 72.1%, tax requirements for 65.0%, a variety of other reasons (e.g., collective agreements, benefits administration, and privacy concerns) for 6.0%, lack of space for 4.9%, administration costs for 4.4%, and company policy for 2.7% of respondents.

B. *Retention and storage of ex-employee biographical and work history details*

After an employee leaves, the average number of years that biographical and work history records are retained is 10.3 years (standard deviation [sd] 8.94 years), and the median time they are retained is 7.0 years, with a minimum of 0 and a maximum of 50 years. One hundred and forty-two workplaces provided a numerical answer, 39 indicated that they retain such information forever, and four did not answer. It was unfortunate that the number of years that workplaces had been operating was not determined.

Ex-employee records are stored on paper by 65.7% of those responding, on paper and computer by 33.7%, on microfiche by 2.2%, on computer by 1.1%, and in some other format by 1.1%. Responses could include more than one category.

The majority of respondents (63.5%) routinely store ex-employee records in human resources locations; 27.4% (50 workplaces) store them in a variety of other locations (e.g., occupational health, administration, archives), 26.5% of these 50 indicating that they store them in finance areas and 2.2% in areas responsible for pensions. Responses in more than one category were permitted.

Table 4 presents the information kept on file for previous employees. Interestingly, 75% or more reported that the following is always retained (in order from highest to lowest): first name, surname, postal code, last known address, date of birth, and salary level(s) or grade(s). On the other hand, 50% or more indicated that the following information is never retained (in order from largest to smallest): ethnicity, nationality, place of birth, maiden name(s), and health insurance number.

TABLE 4
Frequency of information kept about ex-employees (number of workplaces = 185)

Information	Percentage				
	Always	Usually	Sometimes	Never	Missing
Surname(s)	96.8	0.5	0.5	0	2.2
Maiden name(s)	14.6	2.2	13.5	67.0	2.7
First name(s)	97.3	0.5	0	0	2.2
Sex	67.6	4.9	3.8	21.6	2.2
Last known address	90.8	5.4	1.1	0.5	2.2
Postal code	93.0	4.3	0.5	0	2.2
Place of birth	14.1	0.5	5.9	76.8	2.7
Nationality	4.3	1.6	2.7	88.6	2.7
Ethnicity	2.2	0	2.7	92.4	2.7
Date of birth	90.3	3.2	1.1	3.2	2.2
Marital status	55.7	10.8	12.4	18.9	2.2
Next of kin	44.3	9.7	18.4	25.4	2.2
Number of children	22.7	9.2	19.5	46.5	2.2
Health insurance number	29.7	5.4	7.0	55.7	2.2
Staff identity number	73.5	3.2	3.2	17.8	2.2
Job titles held	72.4	11.9	6.5	7.0	2.2
Start and end dates for each job	68.1	10.8	7.0	11.9	2.2
Location (site/plant)	54.6	9.7	6.5	27.0	2.2
Department/work group/ section/work area	62.2	13.0	4.3	18.4	2.2
Salary level/grade(s)	77.8	10.3	4.9	4.9	2.2
Reason for leaving	71.9	13.0	9.7	3.2	2.2

Of the factors that influence the length of time that employees' records are retained after they leave, company policy was responsible for the highest percentage (65.2%), followed by tax requirements (47.3%), health and safety legislation (36.5%), pension requirements (21.0%), space (16.6%), insurance requirements (15.5%), "other" (e.g., 15.5% for other legislation), storage costs (6.6%), and administration costs (1.1%). This question was in a multiple response format.

Similarly, of the various factors that influence the amount of information retained on previous employees, in the categories already described, company policy was responsible for the highest percentage (70.7%), followed by tax requirements (42.5%), health and safety legislation (33.1%), pension requirements (21.5%), insurance requirements (16.6%), space (14.4%), "other" (e.g., 13.8% for the Employment Standards Act), storage costs (5.0%), and administration costs (2.8%). Again, the respondents were asked to check all answers that applied.

In Table 5, the collection of demographic and occupational information for current and ex-employees is compared. With the exception of date of birth, information about current employees is collected significantly

TABLE 5
Differences between information collected on current and past employees (number of workplaces = 185)

Information	*t* value*	df	*p* value
Surname(s)	0.446	180	0.656
Maiden name(s)	1.000	179	0.319
First name(s)	0.000	180	1.000
Sex	−2.321	180	0.021
Address	−2.719	180	0.007
Postal code	−1.911	180	0.058
Place of birth	−0.425	179	0.671
Nationality	−1.418	179	0.158
Ethnicity	−1.345	179	0.180
Date of birth	2.294	180	0.023
Marital status	−1.680	180	0.095
Next of kin	−3.202	180	0.002
Number of children	−2.153	180	0.033
Health insurance number	−0.599	180	0.550
Staff identity number	−1.890	180	0.060
Job titles held	−2.713	180	0.007
Start and end dates for each job	0.174	180	0.862
Location (site/plant)	−2.511	180	0.013
Department/work group/section/ work area	−2.363	180	0.019
Salary level/grade(s)	−2.947	180	0.004

*Paired *t* test

more frequently (at the 5% level or better) than information about ex-employees on next of kin, salary level, address, job titles held and address, work location, work area, sex, and number of children.

C. Workplace surveillance

Overall, 33.5 % (62) of the workplaces indicated that they provide in-house occupational health services for staff, and only 25.9% (48) undertake occupational hygiene or exposure surveillance in the workplace.

D. Occupational hygiene or exposure records

There are 48 workplaces (25.9%) that undertake occupational hygiene measurements of exposure; 72.9% of these measure exposure to noise, 62.5% to chemicals, 12.5% to biological agents, 12.5% to ionizing radiation, 6.3% to particulates, and 4.2% to "other" exposures (e.g., air quality, dust). Responses could include more than one category.

Multiple response analysis showed that the main reasons for undertaking occupational hygiene measurements are 1) to comply with legal requirements (81.3%), 2) as part of a company surveillance plan (75.0%), and 3) in response to problems as they arise (56.3%).

The predominant types of occupational hygiene measurements made are for individual workers (75.0%), particular locations (77.1%), particular job types (70.8%), and particular tasks (58.3%). This question was in a multiple response format.

The distribution of occupational hygiene or exposure information collected by workplaces is listed in Table 6. Of the 48 workplaces, 75% or more reported that the following information is always collected: location (i.e., site or plant), date of sample, agents measured, and personal protective equipment used; 45.8% never measure plant conditions and outputs.

Occupational hygiene record and plant history information are retained for an average of 16.6 years (sd 13.3), with a median of 10.0 years and range from 2 to 40 years ($n = 48$) and 14 workplaces indicated that occupational hygiene and plant history information is retained forever. It was unfortunate that the length of time the workplaces had been operating was not determined. Multiples response analysis showed that the major factors influencing retention time of hygiene and plant history information are health and safety legislation (81.3%) and company policy (68.8%). Further, the predominant factors that influence the amount of hygiene information retained are also health and safety legislation (83.3%) and company policy (68.8%).

E. Occupational health or medical records

In-house medical or occupational health services were provided by 33.0% (62/185) of the workplaces. A listing of the health information collected by these workplaces is presented in Table 7. The following information is always collected by 50% or more of the workplaces: medical history (62.9%), employment history (58.1%), blood pressure (54.8%), weight, vision, and hearing (all at 53.2%), and height and hobbies (51.6%). Further, 72.6% of the workplaces never collect information about reproductive history, and 61.3% never collect information on biological monitoring.

Factors that influence the amount of information collected about the occupational health or medical records of ex-employees include health and safety legislation (80.3%), company policy (67.2%), insurance requirements (18.0%), and space (8.2%). After an employee has left a workplace, the predominant factors that influence the length of time their records are retained include health and safety legislation (75.0%) and company policy (63.3%). For both amount and retention of information, responses could include more than one category.

F. Some results by workforce size

In order to determine whether some results for current employees varied by workforce size, we examined some demographic and personnel information for companies with 50 to 99 employees (i.e., a small workplace), those with 100 to 199 employees (i.e., a medium-sized workplace), and those with 200 and more employees (i.e., a large workplace). These divisions were based on a desire for fairly even frequencies across categories as well as some perspective on small, medium, and larger workplaces in northeastern Ontario.

The results of these analyses are presented in Table 8, which shows that, of information always collected, surname, first name, and current address were almost universally present. However, for each size of company, substantial improvements in data collection could be made for maiden name(s) and ethnicity. Improvement is needed to enhance the collection of health insurance number, next of kin, marital status, location worked, section/work area/department worked, and job start and end date information. For staff identity number, job titles, and salary levels or grade – information always obtained by 75% to 98% of workplaces – improvement in data collection could be made to some extent.

When we considered the influence of workplace size on whether current employee records are held on paper and computer, there was no apparent trend (61.3% (n = 46), 57.1% (n = 32), and 79.2% (n = 42) for small, medium and large workplaces respectively). When we examined whether legislation influences the amount of information collected on current employees by workplace size, a slight increasing trend was detected (67.6%, n = 50; 67.9%, n = 38; and 83.0%, n = 44 respectively). A similar trend was observed for storage costs (68.9%, n = 51; 69.6%, n = 39; and 90.6%, n = 48). When payroll administration was considered, there was no apparent trend (74.3%, n = 55; 67.9%, n = 38; and 77.4%, n = 41), and similar results were observed for tax requirements (64.9%, n = 48; 58.9%, n = 33; and 71.7%, n = 38). All of these could have multiple responses.

TABLE 6
Distribution of occupational hygiene or exposure record information routinely collected for hygiene measurements (number of workplaces = 48)

Information	Percentage				
	Always	Usually	Sometimes	Never	Missing
Location (e.g., site/plant)	91.7	6.3	0	2.1	0
Date of sample	87.5	10.4	0	2.1	0
Unique sample number	45.8	18.8	10.4	25.0	0
Agents measured	79.2	4.2	2.1	14.6	0
Units of measurement	66.7	12.5	0	20.8	0
Type of sample (e.g., grab, personal)	66.7	10.4	4.2	14.6	4.2
Job tasks sampled	54.2	8.3	8.3	25.0	4.2
Sampling strategy (e.g., worst case compliance)	45.8	10.4	6.3	33.3	4.2
Sampling method	56.3	12.5	2.1	27.1	2.1
Sampling duration	58.3	10.4	4.2	25.0	2.1
Method of sample analysis	54.2	18.8	2.1	22.9	2.1
Quality assurance	45.8	4.2	6.3	39.6	4.2
Environmental conditions	50.0	10.4	6.3	29.2	4.2
Plant processes involved	41.7	14.6	6.3	33.3	4.2
Plant conditions, outputs	31.3	10.4	8.3	45.8	4.2
Route of exposure (e.g., skin, inhalation)	62.5	14.6	2.1	18.8	2.1
Personal protective equipment used	77.1	8.3	2.1	10.4	2.1
Workers details (e.g., name, job title)	64.6	12.5	6.3	14.6	2.1

When the median times of retention of ex-employee biographical and work history details were considered, there was no difference by workplace size (median = 7.00 years).

When asked to identify all factors that influence the length of retention of employee records, 19.2% (n = 14), 19.6% (n = 11), and 9.6% (n = 5) of respondents respectively listed space. Health and safety legislation was considered a factor by 24.7% (n = 18), 48.2% (n = 27), and 40.4% (n = 21) respectively, and company policy was a factor for 67.1% (n = 49), 57.1% (n = 32), and 71.2% (n = 37) respectively.

The percentage of small, medium, and large workplaces that undertake occupational hygiene or exposure measurements (n = 48) is 13.5%, 27.3%, and 44.2% respectively. In similar order, the percentage of workplaces that provide in-house medical or occupational health services for staff (n = 62), by company size, was 23.6%, 32.7%, and 52.9% respectively.

Discussion

The response rate in this study (42.6%) was lower than desirable and could compromise the generalizability of the results. The rate was not unexpected, given that the responses were voluntary, and it compares with the rate of 46% of Rushton and Betts in the European Economic Community.[3] As suggested by Rushton and Betts,[4] non-respondents may have more inferior record collection and retention practices than those who did participate in the study.

TABLE 7
Distribution of routinely collected health information (number of workplaces = 62)

Information	Percentage			
	Always	Usually	Sometimes	Never
Medical history	62.9	14.5	9.7	12.9
Family medical history	46.8	11.3	9.7	32.3
Employment history	58.1	11.3	9.7	21.0
Reproductive history	11.3	3.2	12.9	72.6
Smoking history	38.7	11.3	8.1	41.9
Alcohol intake	27.4	11.3	14.5	46.8
Hobbies	51.6	14.5	3.2	30.6
Height	51.6	14.5	3.2	30.6
Weight	53.2	12.9	8.1	25.8
Vision	53.2	12.9	11.3	22.6
Hearing	53.2	9.7	12.9	24.2
Blood pressure	54.8	11.3	6.5	27.4
Biological monitoring	19.4	6.5	12.9	61.3
Details of family doctor	43.5	12.9	11.3	32.3

Northeastern Ontario workplaces that participated in this study appeared to routinely collect much of the very basic demographic information for current and ex-employees (e.g., surname, first name, date of birth, and current address) that is needed for occupational cohort, case-control, and cross-sectional studies. Given that such information is frequently used to link external records, such as various health events, in occupational epidemiological studies, it is reassuring that the recording practices of demographic or biographical data for current and past employees were quite similar throughout northeastern Ontario. However, improvements could be made in the collection of such information as ethnicity, nationality, place of birth, maiden name, and health insurance number, the latter particularly valuable for record linkage purposes and reduction of costs associated with linkages.[3]

For current staff, salary levels or grades, staff identity (or employee) number, and job titles were fairly well collected, but some improvements could be made in the collection of location, site, or plant; section, work area, department, or work group; and start and end dates for each job. In addition, despite the limitation of not determining the length of time that workplaces have been in operation, it may be problematic that ex-employee and work history information is not retained for longer periods and that the predominant type of storage of this information is on paper rather than computer. Much of this kind of information for current and ex-employees is essential for various types of occupational epidemiological studies and for studies of large numbers of subjects, and it can take a great deal of time to enter such data and verify its quality.

It was not surprising that demographic and occupational information was generally collected better for current than ex-employees. Given the importance of such information in epidemiological studies, this is an area for additional education.

It is not surprising that only a small percentage of workplaces reported collection of occupational hygiene or exposure record information, given that collection of that type of information would not be relevant for some; unfortunately, relevance was not determined in this study. However, from the reporting workplaces it was clear that information on location, sample dates, agents measured, and personal protective equipment was fairly well collected, but improvements could be made for several other more detailed factors listed (e.g., plant conditions and outputs, plant processes involved, quality assurance, and sampling strategy, such as worst case or compliance), unique sample number, and workers' details. The great influence of health and safety legislation on the amount of this type of information collected and its retention time was evident. Obviously, it will be also be important to emphasize that inaccuracy and misclassification of exposures limit identification of risk factors.[5] It would also be helpful for future studies to determine to what extent workplaces with exposures of concern are not collecting this type of information and the reasons related to this decision.

Rushton and Betts indicated that some industry-based bodies and professional societies are developing guidelines in response to concern surrounding the existence and quality of workplace records, and such guidelines may influence future practice in other workplaces. In addition, it will be important to determine how adequate available occupational hygiene information is in linking an individual worker with a health outcome to timing, duration, frequency, and magnitude of exposure. In northeastern Ontario, education is required regarding the value of good unique identification in occupational epidemiological studies.

About a third of participating workplaces reported in-house collection of occupational health or medical record information, although this, too, may not be relevant for some workplaces (relevance was not evaluated). In their survey in the European Economic Union, Rushton and Betts indicated that 26% of companies reported in-house occupational health services.[4] Similarly, this type of information was not well collected in the present study, such that current epidemiological studies would need to acquire the information by some other method and consider modification of this behaviour for the future.

Future studies of this nature could gear specific questions to their region of interest (e.g., questions about particular occupational exposures that are prevalent in the region) along with information about periods, duration, frequency, and magnitudes of exposure. Such studies could also ascertain whether particular workplaces plan to perform occupational epidemiological health studies and might require future assistance. As well as using quantitative instruments it could also be helpful to conduct qualitative research using focus groups with compliant and less compliant workplaces for information gathering and educational intervention purposes.

It is necessary to enhance the collection and retention of biographical, occupational exposure, and occupational health and medical information in northeastern Ontario and to establish clear objectives about the collection and retention of such data. In addition, it should be precisely determined what data should be collected and retained and whether the information will be able to provide reasonably good unique identification. The European Economic Commission held a workshop to discuss such issues as

- identification of a minimum dataset to be collected and retained for all employees
- appropriate methods for secure retention
- increasing industrial awareness of the importance of record keeping for health and safety reasons, and
- participation of governmental health and safety bodies and joint employer and employee organizations.[3,4]

With funding, this approach could be adopted in northeastern Ontario and perhaps at provincial and national levels.

Rushton and Betts also recommended that

- records should uniquely identify an individual worker and facilitate linkage to occupational exposure and health effects information
- record format be accessible, suitable for record linkage, and secure, and

TABLE 8
Demographic information routinely collected by 185 workplaces on recruitment of employees by workforce size

Information*	Percentage				
	Always	Usually	Sometimes	Never	Missing
Surname(s)					
Small (n = 76)	96.1	3.9	0	0	–
Medium (n = 56)	100.0	0	0	0	–
Large (n = 53)	98.1	1.9	0	0	–
Maiden name(s)					
Small	15.8	1.3	9.2	73.7	–
Medium	10.7	7.1	8.9	73.2	–
Large	13.2	0	22.6	64.2	–
First name(s)					
Small	97.4	2.6	0	0	–
Medium	100.0	0	0	0	–
Large	100.0	0	0	0	–
Sex					
Small	78.9	5.3	3.9	11.8	–
Medium	67.9	3.6	3.6	25.0	–
Large	77.4	5.7	1.9	15.1	–
Ethnicity					
Small	2.6	1.3	3.9	92.1	–
Medium	5.4	0	3.6	91.1	–
Large	3.8	0	7.5	88.7	–
Current address					
Small	97.4	2.6	0	0	–
Medium	98.2	1.8	0	0	–
Large	98.1	0	1.9	0	–
Date of birth					
Small	82.9	5.3	1.3	10.5	–
Medium	82.1	7.1	0	10.7	–
Large	92.5	1.9	0	5.7	–
Health insurance number					
Small	28.9	5.3	2.6	63.2	–
Medium	32.1	3.6	7.1	57.1	–
Large	35.8	1.9	5.7	56.6	–
Next of kin					
Small	47.4	13.2	9.2	30.3	–
Medium	55.4	5.4	16.1	23.2	–
Large	67.9	11.3	7.5	13.2	–
Marital status					
Small	56.6	10.5	6.6	26.3	–
Medium	55.4	10.7	8.9	25.0	–
Large	75.5	9.4	3.8	11.3	–
Staff identity number					
Small	75.0	6.6	7.9	5.3	5.3
Medium	80.4	12.5	1.8	3.6	1.8
Large	92.5	5.7	1.9	0	0

cont'd

TABLE 8 (*cont'd*)
Demographic information routinely collected on recruitment of employees by workforce size

Information*	Percentage				
	Always	Usually	Some-times	Never	Missing
Job titles					
Small	75.0	3.9	0	3.9	0
Medium	80.4	1.8	0	3.6	8.9
Large	84.9	0	0	0	15.1
Start and finish date for each job					
Small	60.5	13.2	6.6	5.3	14.5
Medium	71.4	7.1	8.9	1.8	10.7
Large	75.5	7.5	11.3	0	5.7
Location (i.e., site/plant)					
Small	50.0	7.9	5.3	5.3	31.6
Medium	60.7	5.4	7.1	3.6	23.2
Large	83.0	3.8	5.7	0	7.5
Section/work area/department					
Small	61.8	6.6	6.6	3.9	21.1
Medium	71.4	10.7	7.1	1.8	8.9
Large	81.1	5.7	5.7	0	7.5
Salary levels/grade					
Small	77.6	10.5	2.6	1.3	7.9
Medium	87.5	5.4	1.8	3.6	1.8
Large	98.1	1.9	0	0	0

* Information obtained from companies designated "small" (with 50–99 employees), "medium" (with 100–199 employees) and "large" (with ≥ 200 employees)

N/A = not applicable

- data be retained by an identifiable organization with a secure chain of custody in case a company goes out of business[3]

Additionally, we recommend that personnel, occupational exposure, and medical information within workplaces be entered into databases that are compatible and easily linked. It is also important to establish the completeness and validity of data from such types of secondary sources[4] and to ensure that records are secure and adequately stored when research may be conducted with such data.[10]

Furthermore, if collection of the information remains voluntary, the use of this type of information in occupational epidemiological studies could remain limited, since occupational epidemiological surveillance and etiological research are limited and, if done at all, take longer and cost more to undertake. Thus, it would appear timely to bring together governmental, occupational epidemiological, hygiene, and health researchers with policy makers in Canada, with national, provincial, and local representation, to discuss these issues further. They should consider the value of developing standards or guidelines for the collection, retention, and relevance of the basic biographical, occupational, and occupational exposure information, and medical records.

In addition, these groups could consider the possibility of national surveillance databases of demographic and occupational exposure factors, and occupational medical records for current and ex-employees, particularly the value of and challenges to achieving consistency.[11,12] Kauppinen and Toikkanen recommended development of a uniform, comprehensive, and continuously developing occupational surveillance system that is valid, current and easy to use.[13] It is encouraging that both European and American groups have been discussing essential elements for occupational databases and how to promote their adoption by public and private sectors.[4,14,15] It would be helpful to have their participation at the proposed Canadian discussions. The American-based NIOSH (the National Institute for Occupational Safety and Health) Hazard Surveillance Team is currently recommending that a new national, on-site survey be conducted to update information on the distribution of health and safety hazards and exposures in regulated industries.[16]

It is essential that the importance of collecting and retaining biographical, occupational exposure, and health record data, as well as the confidentiality of such data, should receive additional attention from workplaces, researchers, government, and policy makers in northeastern Ontario, provincially and nationally. Without such information, health and exposure surveillance in occupational epidemiological studies and workplace disease etiology studies will be extremely limited, and much more time-consuming and costly from a human health and workplace perspective. Kauppinen and Toikkanen emphasize that regular analyses of occupational surveillance information by competent individuals with appropriate follow-up and action may be one of the most effective preventive and health promotion measures in the workplace.[13]

Although some workplaces may be suspicious of such external involvement and knowledge about their workplaces, the savings generated from prevention, reduction, and/or early detection of diseases and injuries, as well as from associated compensation, should be convincing.

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Cross-Country Forum

The Ontario Sun Safety Working Group

Loraine D Marrett, Dave Broadhurst, Stephanie Charron, Laurie Fraser, Lynn From, William Hunter, Patricia Payne, Mary Louise Yarema and Cheryl Rosen

Background

Solar ultraviolet radiation is classified by the International Agency for Research on Cancer (IARC) as a carcinogen, causing skin cancer.[1] It also causes a number of other health-related conditions, such as sunburn, photoaging and cataracts.[2] In Canada, the incidence of melanoma, the least common but most life-threatening form of skin cancer, increased by 5–6% per year between 1970 and 1986[3] and more slowly thereafter.[4] In 2002, it is estimated that there will be 3,900 new cases of melanoma and 72,000 new cases of non-melanoma skin cancer.[4] Health Canada has recognized exposure to sunlight as an important health issue, and in the 1990s sponsored two symposia to review the scientific evidence concerning health effects of ultraviolet radiation (UVR), and to identify research and surveillance gaps.[2,5]

"Sun safety", the practice of sun protective behaviours, is increasingly considered an important public health strategy by Canadian health professionals, especially those concerned with cancer prevention. For example, sun safety is included in the Mandatory Health Programs and Services Guidelines under which Ontario's public health units operate, and a set of recommended sun safety messages were developed at a Health Canada workshop.[6]

The National Survey on Sun Exposure and Protective Behaviours found that most Canadians practise insufficient sun protection and that awareness of the need to practise sun protection is not high.[7–9] Sun safety programs and policies in Canada are largely developed and communicated by health professionals, including dermatologists, public health workers, researchers and sunscreen manufacturers, and promoted through organizations like the Canadian Cancer Society, the Canadian Dermatology Association, Health Canada and local health units.[10] In other countries, such as Australia and England, sun safety programs may be disseminated by marketing and health promotion specialists.[10]

The Ontario Sun Safety Working Group (OSSWG) was formed to provide an opportunity for professionals involved in sun safety to work together to enhance sun-related activities. The purpose of this report is to describe the OSSWG as a model that may assist professionals in other parts of the country to more effectively mobilize expertise on sun safety or other public health issues in their regions.

History of sun safety in Ontario

Sun safety activities in Ontario, and across most of Canada, date back to the late 1980s. At that time, several organizations initiated campaigns in response to concerns about both rapidly rising skin cancer rates and depletion of the ozone layer.[10] In 1989, the Canadian Dermatology Association began its national Sun Awareness Week.

Several other national organizations also initiated UVR protection programs with Ontario components, often including Sun Awareness Week as part of their outreach strategies. The Canadian Cancer Society began producing sun safety materials in the late 1980s and elevated "SunSense" to one of its four health promotion priorities in 1993. One year later, its Ontario Division designed and packaged a full suite of sun protection activities to be delivered by its volunteers. Health Canada produced a number of sun protection resources in the early 1990s, including one of the first to emphasize the importance of sun protection for children. Environment Canada launched the daily UV index forecast program, with accompanying support materials, in the spring of 1992. In 1995, the Ontario Ministry of Labour published a "Sun Safety Alert" for outdoor workers and then developed a UVR health and safety guideline governing both solar and non-solar UVR exposures in the workplace. At the local level, individual public health units (e.g., London-Middlesex, Scarborough and others) created innovative sun protection campaigns in their respective communities.

These organizations cooperated on specific projects and loosely coordinated their core sun awareness messages. Individuals representing some of these groups began meeting once a year in 1992 to discuss topical issues such as Sun Awareness Week activities, the status of the ozone layer and

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recent research and policy developments in the field.

The Ontario Sun Safety Working Group

Membership and purpose

By the mid-1990s, several federal, provincial and municipal government departments and ministries, as well as health organizations, had resources dedicated to UVR protection in Ontario. Several of these groups identified the need for a more coordinated and dedicated approach to the provision of sun safety information to the public and policy makers, and the need for an enhanced profile for sun protection issues, especially in high-risk populations such as children and outdoor workers. In response to these needs, the Ontario Sun Safety Working Group was formed in 1997 as a partnership of individuals and organizations concerned with the impact of solar and artificial UVR on health. The OSSWG's stated purpose is to promote healthful behaviours and policies in relation to UVR exposure. Current member organizations and titles of their current representatives are shown in Table 1.

The OSSWG meets monthly between September and June. Meetings involve planning and coordination of activities, examination of scientific developments in the field, updates on initiatives in member organizations and the coordination of sun protection messages among members.

Goals and activities

The OSSWG has the support of its member organizations in terms of the commitment of the professionals who form its core. In its early days, the major foci were the professional development of OSSWG members and attendance at public events where promotion of sun safety was relevant (e.g., Cottage Life Show, Royal Winter Fair, garden shows, etc.). However, as the group developed, it began to broaden its scope and undertake more challenging work. The goals of the OSSWG and some of its activities are listed in Table 2. A sample of activities is described in more detail below.

TABLE 1
Ontario Sun Safety Working Group: Member organizations and representatives

Organization	Title of representative/ area of expertise
Canadian Dermatology Association	Dermatologist
Environment Canada, Ontario Region	Meteorologist
Cancer Care Ontario	Epidemiologist
Ontario Ministry of Health and Long-Term Care	Public Health Inspector
Ontario Public Health Units	Public Health Nurse
Health Canada, Ontario/Nunavut Region	Health Educator
Canadian Cancer Society – Ontario Division	External relations/ Cancer control
University of Toronto, Department of Medicine, Division of Dermatology	Dermatologist

TABLE 2
Ontario Sun Safety Working Group: Goals and sample activities

Goal	Sample Activities
Gathering and evaluation of information on the health impact of UV radiation exposure and the effectiveness of protective behaviours	Expert evaluation of sun safety materials; participation in the Canadian Health Network's Skin Cancer Task Force
Identification and development of key information/educational materials	Preparation and dissemination of report on Ontario results from the National Survey on Sun Exposure and Protective Behaviours; development of elementary school health and science curricular materials; production of a sun safety manual for outdoor workers
Raising awareness on the effects of solar and artificial UV radiation on human health	Presentations at the Ontario Ministry of Health and Long-Term Care's Public Health Days, at an annual meeting of the Association of Science Teachers of Ontario, and at dermatology and other medical rounds; information presentations at fairs and shows; meetings with Toronto District School Board and Evergreen
Promotion of consistent public health approaches (personal and institutional) to sun safety	Input to Sun Awareness Week themes and activities; consultation with Atlantic Region of Environment Canada in the development of Public Service Announcements; development of an Ontario Sun Safety Network
Advocacy for policies to reduce UV radiation exposure	Participation in the Toronto Cancer Prevention Coalition; writing letters and making representations to Toronto Board of Health

Gathering and evaluation of information on the health impact of UV radiation exposure and the effectiveness of protective behaviours:

OSSWG members routinely bring new communication materials from their organizations to the meetings. This results in continuing education of members and promotes use of uniform materials and messages. The group also evaluates and provides feedback on these materials.

The Canadian Health Network is being developed by Health Canada as a reliable Canadian Internet source of health information. The Canadian Cancer Society (CCS) was designated as the coordinator of cancer-related information for the Network, and invited the OSSWG to assist in the development of the section on skin cancer. Several members of the OSSWG, along with other Canadian skin cancer and UVR experts and CCS staff, constituted the Skin Cancer Task Force. Since the skin cancer section was the first to be developed by the CCS, the Task Force piloted the way in which web site material would be identified, evaluated and augmented. The Task Force determined the spectrum of information required, evaluated existing web sites, identified information gaps and assisted with the development of "FAQs" (frequently asked questions with answers) to address these gaps.

Identification and development of key information/educational materials:

The OSSWG analyzed Ontario data from the National Survey on Sun Exposure and Protective Behaviours[7–9] to describe the recent sun exposure, protective behaviours and sunburn experience of Ontario adults and children. The results were published as a report[11] that has been disseminated free of charge to Ontario public health units and other interested parties.

When the Ontario elementary school curriculum underwent major changes a number of years ago, OSSWG members identified sections of the science and health curricula where sun safety-related information could be incorporated. Sample teaching materials were developed. Sun safety has now been integrated into an injury prevention lesson plan in the grade 6 physical and health education curriculum.

A sun safety guide for outdoor workers was developed and produced collaboratively with Toronto Public Health and the Canadian Dermatology Association, and has been sold (at cost) to several unions and management organizations.[12]

Raising awareness on the effects of solar and artificial UV radiation on human health:

Members of the OSSWG have made expert presentations to a variety of professional groups. Topics covered included epidemiology of skin cancer, clinical aspects of skin cancer, health effects and biological properties of UVR and sunscreens, physical aspects of UVR (including the state of the ozone layer), and data about the population's exposure to UVR and use of protective behaviours.

Members are also available to speak with the media and have published review articles on sun protection.

Promotion of consistent public health approaches (personal and institutional) to sun safety:

Over the last five years, the OSSWG has supported the dissemination of consistent sun protection messages in Ontario by coordination of outreach campaigns among members, and by providing input to and support for Sun Awareness Week campaigns.

A major project in progress is the development of an Ontario Sun Safety Network. Over the years there have been numerous requests from sun safety professionals in public health units for advice on sun-related issues (e.g., reasonable targets for Ontario public health's Mandatory Health Programs and Services Guidelines, existing day care sun safety policies, etc.) or for closer linkage with the OSSWG and others working in the field. Most public health nurses with the sun safety portfolio in a public health unit work alone, and many have responsibilities in addition to sun safety. The OSSWG therefore secured funding from Cancer Care Ontario for a survey of Ontario sun safety practitioners' activities and needs, and development of a proposal for a network to link those interested in sun safety with each other and with information resources.

Advocacy for policies to reduce UV radiation exposure:

OSSWG members have actively participated in the UVR Working Group of the Toronto Cancer Prevention Coalition, which was charged with making recommendations to the Toronto Board of Health on ways to reduce UVR-related cancers in Toronto. As part of its background work, the UVR Working Group prepared a report reviewing public sun safety policies and programs, both local to Toronto and more broadly. A lack of sun protection policies and/or enforcement was found in the Toronto region. The UVR Working Group made three recommendations for improved sun safety policy and practice in Toronto, one of which (the development of sun protection policies for city employees when working out of doors) has already been acted upon.

Evaluation

The work of the OSSWG has not been formally evaluated. It has, however, created or contributed in a meaningful way to a number of tangible products. These include skin cancer material for the Canadian Health Network, the Ontario report on sun exposure and protective behaviours[11] and the sun safety manual for outdoor workers.[12] These materials have been used as information sources for various purposes, including implementation of sun safety policies in the workplace and the development of sun safety materials and strategies. The OSSWG is increasingly gaining recognition as a source of expertise.

The OSSWG has successfully secured small amounts of funding for two of its projects: the production of the Ontario report on sun exposure and protective behaviours[11] and the development of a proposal for an Ontario Sun Safety Network.

The OSSWG undertook a review and strategic planning exercise in 2000 with assistance from the University of Toronto's Centre for Health Promotion. As a result,

the group decided to adopt one primary focus with a small number of objectives each year, in addition to our ongoing professional education, support and advocacy work. This exercise also led to greater awareness of the need for the OSSWG to be realistic about what it can achieve, since it is a coalition of a small number of busy professionals without regular funding.

The OSSWG's focus for 2001–2002 was the promotion of shade provision in public places. Discussions were held with other organizations that share this goal (e.g., the Toronto District School Board and Evergreen), to identify synergies that would allow each organization to be more effective with limited resources. The OSSWG reviewed "Under Cover",[13] an Australian publication about the provision of quality shade, to determine the extent and nature of revisions required to make it appropriate for use in Canada. Production of a revised version will not be undertaken until there is greater certainty about the level of demand. Some of the OSSWG's members have been instrumental in the organization of a shade conference to be held in 2003. The main focus for 2002–2003 will be the development of the Ontario Sun Safety Network, while continuing the work on provision of shade.

Challenges

There are a number of challenges facing the OSSWG. One of these is turnover of membership when people are reassigned to other portfolios or jobs. Another is lack of resources. The amount of time each member can give to the group's activities is limited. Apart from the two funded projects noted above, the OSSWG has had to support its activities solely from the resources represented by the members and their associations/employers. This has limited the scope of work.

In the early 1990s, the fear of ozone depletion in northern latitudes and the dramatic rise in skin cancer rates received considerable public attention. A decade later, with comprehensive controls on ozone-depleting substances in place, UVR and skin cancer are now viewed as mature public health and environmental issues. Yet skin cancer rates remain stubbornly high, and it continues to be challenging to maintain momentum and secure media attention. This situation underscores the need for a multi-agency team, such as the OSSWG, that can serve as an effective vehicle for collaboration on sun safety initiatives and media opportunities. The OSSWG acts to support and maintain a critical mass of professionals addressing this health promotion issue.

A positive challenge has been the interest on the part of Ontario public health unit staff working in sun safety to join the OSSWG. This interest has stimulated the OSSWG to investigate development of a sun safety network so its outreach can be extended, without making the core group too large.

The model adopted by the OSSWG works in part because of the critical mass of interested individuals with varied expertise located within a small geographic area. Although there is currently one "long-distance" member who usually joins the meetings by telephone, experience indicates that it is difficult to maintain involvement when connection is only by telephone and e-mail.

Conclusions

The OSSWG has been successful in accomplishing its mission because of the commitment, energy and enthusiasm of its members and their organizations. The OSSWG provides valuable support to health professionals who may be rather isolated with respect to their sun safety work. Because of its cross-organization, multi-disciplinary nature, it represents an invaluable source of knowledge, expertise and support for both its members and other individuals and organizations with an interest or mandate in sun safety. Because of its critical mass, the OSSWG is able to take actions and to introduce change much more effectively than individual members working on their own.

We recommend that those wanting to start a group such as the OSSWG for sun safety or other public health program areas

- identify individuals with a broad range of expertise and from a range of organizations
- establish a critical mass of members
- develop a mission statement, terms of reference and a *modus operandi*
- think carefully about priorities, and limit work to one or two main areas at a time
- re-evaluate from time to time to ensure you stay on track
- capitalize on the ability of a multidisciplinary team to comprehensively address issues
- develop projects that generate enthusiasm among its members

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Workshop Report

A call for action to support best practices in evaluation of comprehensive tobacco control evaluation strategies

Steve Manske, Catherine Maule, Shawn O'Connor, Chris Lovato and Dexter Harvey

Abstract

The National Tobacco Control Best Practices Working Group convened a two-day workshop to support best practices in evaluation of comprehensive tobacco control strategies. A Better Practices Model, aimed at developing a self-correcting system for best practices, guided the workshop content and process. Organizers intended to identify a common surveillance and monitoring framework for tobacco control strategies in Canada by first building strong working relationships between 43 decision-makers, practitioners and researchers from 12 Canadian jurisdictions. Participants identified needs and recommendations related to increased understanding and use of uniform evaluation strategies, building capacity, and recognition of the complexity of the task of evaluating comprehensive tobacco control strategies. The workshop highlighted the need for increased communication to facilitate understanding across the different sectors of participants. It also identified the potential benefits of harmonization in evaluation of tobacco control strategies across jurisdictions. Priority actions include forming a national team to agree on a model for evaluation, conducting an environmental scan for indicators, planning evaluation/monitoring and research agendas and determining roles for various stakeholders.

Key words: *best practices; comprehensive tobacco control; evidence-based medicine; prevention and control; program evaluation; smoking*

Introduction

Effective public health practice requires informed decisions on the best possible actions to take in tackling complex health problems. These actions – or "best practices" – are "those programs and policies of research and interventions that will have the greatest impact on reducing the current and future burden of disease".[1] This paper describes a workshop held in Toronto on March 25–26, 2002 to support best practices in evaluation of comprehensive tobacco control strategies.

The Workshop was convened by the National Tobacco Control Best Practices Working Group* (Working Group), a collaboration of Canadian organizations committed to the identification and implementation of best practices for tobacco control programs and policies. Tobacco control is an appropriate focus since the potential health impact is great, and 30+ years of tobacco control practice and research have resulted in an extensive evidence base. Nonetheless, the concepts and processes guiding the Working Group could have equal application to other complex health problems such as sedentary lifestyles and poor nutrition.

Context for the workshop

A model for identifying, implementing and evaluating better practices

The Working Group employs a better practices model[2] that specifies three phases:

Phase 1: identify recommended practices and tools (review of what we know)

Phase 2: disseminate, implement and evaluate effectively

Phase 3: use these results to inform future practice

Phase 1 takes advantage of the present knowledge base to identify a set of recommendations and tools in a particular topic area. To achieve this end, the model requires the identification of a clear question

* Member organizations at the time of the workshop were: the Canadian Council on Tobacco Control (CCTC); the Canadian Tobacco Control Research Initiative (CTCRI); the Centre for Behavioural Research and Program Evaluation (CBRPE); and Health Canada. Health professionals invited to assist with workshop development were drawn from Health Canada, Ontario Tobacco Research Unit, University of British Columbia and University of Manitoba. Funding for the workshop was provided by CBRPE, CTCRI, and Health Canada.

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and filtering of evidence on the question through a scientific lens. Subsequent critical steps within Phase 1 involve the filtering of evidence through a lens reflecting practical experience, including plausibility and expert advice. Phase 1 concludes with the creation of a toolkit that may consist of program or policy interventions, guidelines for new research, or some combination of the two. The belief that both scientific and practice lenses are necessary to identify best practice distinguishes this approach. Most other frameworks have limited their search for optimum interventions to those scientifically validated,[3,4] without further consideration of a context based on practice.

Steps in Phase 2 require that the dissemination, adoption and implementation processes encourage understanding of the way recommendations fit the new context in which they will be applied. There is, however, a fallacy in assuming that we can transfer recommendations to a new context or time.[5] Therefore, the final step in Phase 2 helps users evaluate the extent to which they have achieved a best practice.

Phase 3 directs users to incorporate the results of their evaluation back into the planning of future interventions and research (i.e., Phase 1). In doing so, users will create an iterative, self-correcting system. The model uses the term "better practices" rather than "best practices" because recommendations cannot be regarded as permanent, universal gold standards, given that the context constantly changes.

The workshop was intended to develop one component of such a self-correcting better practices system on a national scale. That is, organizers wanted to identify a common surveillance and monitoring framework for comprehensive tobacco control strategies in Canada, and encourage effective adaptation of the framework for use in each jurisdiction. At present, Canada lacks a common framework. Other jurisdictions have developed such frameworks (e.g., Massachusetts,[6] California,[7,8] and Arizona.[9] The United States devoted efforts to the establishment of comparability across states through the ASSIST program.[10] ASSIST facilitated use of the framework through technical assistance and training.

If the 14 Canadian jurisdictions (one national, 10 provincial, three territorial) adopt a common surveillance and monitoring framework, decision-makers could take advantage of the natural experiments across jurisdictions and compare experiences to improve practices. Ongoing surveillance and monitoring of the national, provincial and regional strategies are key to helping direct the types of data needed to facilitate evidence-based decision-making related to the objectives at each jurisdictional level. Linkage of objectives and evaluation helps to ensure outcomes are achieved and dollars are spent wisely.[11]

Need for evaluation of comprehensive tobacco control strategies

Tobacco remains the primary preventable public health concern in Canada,[12–16] with epidemiological evidence of its devastation growing steadily.[14] While tobacco is most commonly linked with lung cancer, it is associated with a variety of other cancers, cardiovascular disease, COPD, and diabetes as well.[17] This also leads to severe economic and social consequences.[18–20]

In response, government and non-government organizations have directed systematic efforts toward tobacco control. While the prevalence of tobacco use has abated somewhat with 22% of adults smoking,[21] tobacco control remains a priority health issue. Evidence accumulated over four decades points to the need for comprehensive tobacco control efforts. Jurisdictions that have demonstrated reductions in population-level smoking rates (e.g., California, Florida, Massachusetts) have employed comprehensive, co-ordinated strategies.[7,22,23] Similarly, comprehensive interventions have shifted population health patterns substantially for a variety of diseases (e.g., CVD[24] cancer[25]). While other countries' experiences can inform Canadian practice, our earlier review of the Better Practices Model[2] indicates that any strategies will require adaptation, and subsequent evaluation, in Canadian settings.

Principles guiding efforts to identify and implement better practices for evaluation of comprehensive tobacco control strategies

The collaboration of researchers and potential users of recommended practices is critical to the process of using the Better Practices model. While their respective expertise in science and practice contributes to an improved set of recommendations, this collaboration is not necessarily simple. The Working Group applied its own "better practices" principles, using the Communities of Practice model[26,27] to guide efforts to build collaboration.

Communities of Practice (CoP) consist of groups of individuals with a common purpose, regularly interacting to develop shared understandings and practices.[26–28] Because collaborators attending the workshop came from varied backgrounds (e.g., Nova Scotia and British Columbia; research and practice), the CoP model suggests mutual engagement could help develop trust among participants. Only when collaborators established trusting relationships could the community negotiate a common purpose and hold each other accountable to what this purpose means. With time, collaborations develop a shared way of describing and acting on these purposes. The Working Group hoped to help build a CoP between researchers and decision-makers to develop a common framework for evaluation of comprehensive tobacco control strategies.

The Working Group chose a workshop, a face-to-face format, to engage potential collaborators. The Group recognized, however, that the resulting CoP would require some form of electronic communication such as telephone, e-mail and the Internet to further develop and maintain its activities. While geographically dispersed CoPs in large businesses often rely on electronic communication, they benefit from initial face-to-face interactions to establish personal relationships that build trust and confidence between CoP members.[29] Dispersed CoPs are more successful when members share similar values, codes, and stories.[30,31]

Background work

Prior to the workshop, background research was completed on existing evaluation strategies, frameworks and resources used in the United States. The workshop was intended to share this information with key leaders in Canadian provinces and territories. Overall, the workshop strove to achieve the best results from these evaluation frameworks and to share them across jurisdictions. This would help decision-makers adjust tobacco control programs using evidence of effectiveness. The *vision* for the workshop was to

- develop a common approach to evaluation, where possible and appropriate
- facilitate the process of developing high quality evaluations yielding greater value through commonality of approaches
- support best practices in evaluation to address issues of accountability.

The objectives of the workshop were to

- **foster networking and information exchange** within and between the provinces and the tobacco control sectors (research/evaluation, practice, and decision-making)
- **identify principal, common components of tobacco control strategies or interventions** among different jurisdictions
- **ascertain** (in broad terms) what **information** is required from an evaluation of these common elements/interventions **to guide ongoing decision making**
- **explore interest in developing common indicators** and establishing processes that would streamline evaluation across jurisdictions, supporting more efficient information gathering and decision making; initiate ideas on how to accomplish this
- **plan specific future steps** toward the development and implementation of provincial evaluation plans related to core tobacco control activities (incorporating existing data collection systems), focusing on areas where joint efforts would be advantageous for advancing the work of those responsible for implementing tobacco control strategies, interventions, and evaluations.

Summary of workshop proceedings

The 43 participants included 11 public health practitioners (e.g., provincial voluntary organization tobacco control practitioners), 15 decision-makers (e.g., provincial tobacco strategy coordinators), and 17 researchers representing 10 provinces, one territory and the federal perspective. On Day One, discussion centred around five domains from the background work that was identified as the potential basis of an evaluation framework or logic model. These domains could be used to map inputs and outcomes of: capacity and resources for tobacco control; policy efforts to control tobacco; program efforts to control tobacco; research, monitoring and evaluation of tobacco control; and collaborative partnerships. Discussion covered a broad range of issues, including recommendations for improving current approaches, indicators that would demonstrate the success of activities in each of the domains, and challenges and barriers to demonstrating success.

On the second day, discussions focused on the evaluation of activities addressing three of the goals of the National Strategy[†] (prevention, protection, and cessation. De-normalization, the fourth goal, was not addressed.) and what is needed to implement the evaluation of *comprehensive* programs addressing multiple objectives.

Through a series of small group and plenary exercises, participants identified evaluation needs and strategies from the perspectives of different jurisdictions, decision-makers, practitioners and researchers. These needs centred around three themes: increasing understanding and use of uniform evaluation strategies; building capacity through financial and policy support and tools that facilitate evaluation; and developing strategies that address the complexities of implementing evaluations. The three themes may be summarized as follows:

Understanding and use of evaluation strategies

- share information about activities and tools to enhance the quality of tobacco control activities
- increase coordination and participation among key stakeholders/decision-makers in tobacco control. This includes building relationships between and among the research, practitioner and decision-maker communities to facilitate the gathering and use of information on intervention approaches.

Capacity

- integrate evaluation into all program plans by, for instance, designating a percentage[‡] of budgets for the purposes of evaluation and collecting data prior to and throughout the implementation of any intervention
- monitor and advocate for change in health professionals' perceptions about tobacco issues, their roles in addressing tobacco use, and the actions they take in tobacco control

Complexity

- capture information specific to each of the goals of prevention, protection, cessation and de-normalization
- recognize that the interplay and complexity of contributing factors related to a jurisdiction's comprehensive strategy is important, whether evaluating a single activity or a range of activities. For example, consider market segmentation, determinants of health, knowledge and attitudes, as well as

[†] Steering Committee of the National Strategy to Reduce Tobacco Use in Canada. *New Directions for Tobacco Control in Canada: A National Strategy*. Public Works and Government Services of Canada (1999).

[‡] Based on the experience of California and on information from the US Centers for Disease Control and Prevention, a reasonable estimate may be 10% for evaluation of individual community interventions, and an additional 10% for evaluation of the overall comprehensive program.

behaviours associated with tobacco use, and context

- monitor the impact of interventions for a substantial period of time following completion of the intervention to assess maintenance of impact
- consider a range of ethical, human rights, and legal implications when implementing and evaluating many interventions

Recommendations

These **major recommendations** emerged from the identification of these needs

- **develop systems for sharing information across jurisdictions in Canada,** such as toolkits of standard measures and methods to exploit technologies, and a clearinghouse of surveillance data and existing evaluation resources
- **create mechanisms to support networking and coordination,** such as evaluation-specific tracks or meetings at national conferences, online communities of practice and clear terms of reference for partnerships
- **develop and disseminate clear and consistent definitions and objectives**, such as a common *language* and understanding of evaluation to facilitate information sharing, and tangible objectives (e.g., percent reductions in number of users) to track progress toward meeting the goals of a jurisdiction's comprehensive strategy. We need to reach a consensus on the meaning of "comprehensive" tobacco control and definitions for "smoker" and "quit"
- **build financial resources** to increase commitment to evaluation by expanding existing financial resources and seeking new sources of funds by encouraging stable and sustainable funding, perhaps via a dedicated tobacco tax. Guidelines must be established for per capita funding on tobacco control and evaluation
- **increase capacity to guide evaluation at the local levels** by creating a national network or expert advisory committee to assist with the collection and interpretation of data in order to "re-tool" researchers to support communities
- **increase political and community support for tobacco control** by using data from periodic surveys of attitudes and beliefs as advocacy tools
- **monitor other factors that are not a direct part of tobacco control interventions**, including tobacco industry activities, resources, and profit margins
- **develop and disseminate fundamental practices that connect tobacco control strategy objectives to outcomes**. The practices might include
  - establishing benchmarks of realistic targets for outcomes
  - supporting systematic (best practice) reviews and knowledge translation
  - using and reporting negative results and unintended consequences
  - considering regular feedback through provincial report cards
  - monitoring the utility and impact of *evaluation* practices,
  - supporting evaluation through "arms-length" independent mechanisms where possible

Workshop participants identified the following priority actions to support the development of a framework for evaluating comprehensive strategies:

- conduct an environmental scan to determine gaps and to identify indicators internationally, nationally and provincially
- plan evaluation/monitoring and research agendas, recognizing capacity issues
- form a national team to agree on a model for evaluation (including definitions), a coordinating mechanism, a database warehouse, ways to integrate data, data sources (vital statistics, etc), research agenda and priorities
- identify roles and responsibilities for various levels (federal, provincial/territorial) and sectors (governmental, non-governmental, research)

Discussion

The workshop results demonstrate the need to develop actions to facilitate the evaluation of comprehensive tobacco control strategies in Canada and a national system to support best practices in this area. This will require particular attention to the complexity of such efforts, the additional capacity, in terms of resources and tools, and the improved sharing and coordination of evaluation. Workshop participants identified recommendations for mechanisms and products to address these needs.

The need for, and difficulty in achieving, effective knowledge translation was a common theme throughout the deliberations. For example, participants from the program/decision-maker sector tended to use different language than the research/evaluation sector when referring to similar concepts. The importance placed on concepts also varied by sector. The workshop started a dialogue, but to achieve Wenger's concept of a community of practice with shared *understanding* and agreement across these different sectors, jurisdictions and organisations will require more interaction among key stakeholders. Greater information exchange (e.g., of logic models) among participants, prior to the workshop, would have aided understanding at the workshop. To pursue the results of the workshop, participants are using various forms of electronic networking. These include *QuickPlace*™ web-based software to permit creation of member profiles and facilitate development and sharing of expertise and practical tools, such as surveys and protocols related to comprehensive tobacco control evaluation.

The workshop also highlighted the lack of guidelines for the evaluation of comprehensive tobacco control strategies. Participants agreed that adopting a common evaluation framework across jurisdictions would lend itself to many benefits. Such coordination would, for example, capitalize on the natural experiments occurring

when one or more provinces implement particular policy changes, while others do not. It would also make possible economies of scale, in which tools and protocols developed in one jurisdiction are shared with others.

The Working Group anticipates that the actions it identified as priority will contribute to a framework for evaluation, including a statement of purpose, definitions and timelines for interventions, and a standard minimal set of data collected in all evaluations of comprehensive strategies. These actions will also contribute to an update of an overview of existing efforts to monitor and evaluate, a template to compare provincial level best practices and to evaluate evidence that is sensitive to the content and form of decision-makers' needs.

Conclusions

This workshop made significant progress in building relationships among researchers, practitioners and decision-makers within and between territorial, provincial and federal jurisdictions. In doing so, the workshop achieved its objectives but the tobacco control community faces considerable work to achieve its vision.

Workshop participants established, in broad terms, the information required from the evaluation of core elements/interventions to support ongoing decision-making. They expressed strong interest in developing common indicators. Further steps following the workshop will further develop processes to streamline evaluation across jurisdictions and support more efficient information gathering and decision-making. The National Tobacco Control Best Practices Working Group is pursuing funding and other resources to implement the recommendations.

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Calendar of Events

April 9–11, 2003 **Melbourne, Australia**	"Tobacco Control: A Blue Chip Investment" 2nd Australian Tobacco Control Conference	The Meeting Planners 91–97 Islington Street Collingwood, Victoria, Australia, 3066 Tel.: +61 3 9417 0888 Fax: +61 3 9417 0899 E-mail: tobaccocontrol03@meetingplanners.com.au <http://tobaccocontrol03.conference.net.au>
April 10–12, 2003 **Ottawa, Ontario**	"Changes, Challenges and Choices" 25th National Conference of the Alzheimer Society of Canada	Tel.: (416) 488-8772 Fax : (416) 488-3778 E-mail: conference@alzheimer.ca <www.alzheimer.ca/english/newsevents/conference-intro.htm>
April 22–23, 2003 **Toronto, Ontario**	"Advancing Solutions: The 2003 Future of Health Conference"	Dian Calagoure or Coeur Riley The Conference Board of Canada 255 Smyth Road Ottawa, Ontario K1H 8M7 Toll-free.: 1 800 267-0666 Tel: (613) 526-4249 E-mail: registrar@conferenceboard.ca <https://secure.conferenceboard.ca/conf/apr03/2003Future_Health.htm>
April 23–27, 2003 **Banff, Alberta**	CAPO 2003 6th World Congress of Psycho-oncology	c/o Psycho-social resources Tom Baker Cancer Centre Alberta Cancer Board 1331– 29 Street NW Calgary, Alberta T2N 4N2 Tel.: (403) 670-1767 Fax: (403) 283-6032 E-mail: banffcongress@cancerboard.ab.ca <www.capo.ca>
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September 15–18, 2003 **Atlanta, Georgia, USA**	"Comprehensive Approaches to Cancer Control – The Public Health Role" CDC's 2003 Cancer Conference	Conference co-sponsors include: Centers for Disease Control and Prevention American Cancer Society Chronic Disease Directors National Cancer Institute North American Association of Central Cancer Registries Toll-free: 1 877 426-2746 E-mail: info@cancerconference.net <http://www.cancerconference.net>

September 21–25, 2003 **Orlando, Florida, USA**	5th International Symposium on the Role of Soy in Preventing and Treating Chronic Disease	American Oil Chemists' Society PO Box 3489 Champaign IL 61826-3489 USA Tel.: (217) 359-2344 Fax: (217) 351-8091 E-mail: meetings@aocs.org Information: Mindy M. Cain at: mindyc@aocs.org < www.aocs.org/meetings.soy03 >
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Volume 23 Contents

No 4, 2002

Volume 23 Subject Index

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