CURRENT CONCEPTS

An inventory of information on blindness and visual impairment in Canada

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ABSTRACT • RÉSUMÉ

- **Background:** Several health databases contain information on blindness and visual impairment in Canada. Such databases may permit studies of the outcomes, predictors, economic costs and meta-analysis of ocular health problems and visual disability. In this paper we summarize the existing public health information on blindness and visual impairment in Canada.
- **Methods:** A systematic search was performed to find the information in three areas: health administrative databases, health surveys and registries. Both literature searching and Internet searching were performed. The institutions were notified by email or telephone that information pertaining to vision and blindness was desired. When necessary, we visited the institution to obtain the information.
- **Results:** Health administrative databases contain information on a wide cross-section of diagnoses but are usually limited in detail and seldom provide longitudinal information. Health surveys have a limited amount of systematic information on visionrelated questions and rely exclusively on self-reporting. Registries exist on a wide range of visual topics. The Canadian National Institute for the Blind (CNIB) has the most comprehensive registry.
- Interpretation: This is the first attempt at summarizing all the public health information on blindness and visual impairment in Canada. The present population-based ocular information has numerous shortcomings. More comprehensive validation of large registries, such as that of the CNIB, is needed to provide the foundation for a longitudinal ocular surveillance system. Such a system could guide research on risk factors and the effect of treatment, economic analyses, and public policy for ocular research and service allocation.

Contexte : Plusieurs bases de données sur la santé contiennent de l'information sur la cécité et la déficience visuelle au Canada et peuvent permettre l'étude des résultats, des valeurs prédictives et des coûts économiques ainsi que la méta-analyse des problèmes de santé oculaire et d'incapacité visuelle. Cette recherche résume

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- l'information actuelle du domaine de la santé publique sur la cécité et la déficience visuelle au Canada.
- Méthodes : On a fouillé systématiquement trois secteurs : les bases de données administratives, les enquêtes sur la santé et les registres de la santé, accessibles dans la littérature et Internet. Les institutions ont été informées par courriel ou téléphone de notre désir d'obtenir de l'information sur la vue et la cécité et, au besoin, nous les avons visitées à cet effet.
- **Résultats :** Les bases de données administratives contiennent un large éventail d'information transversale sur les diagnostics, mais une quantité ordinairement limitée de détails et rarement de l'information longitudinale. Les enquêtes sur la santé contiennent une quantité limitée d'information systématique en ce qui a trait à la vue et reposent exclusivement sur les renseignements personnels. Les registres couvrent une vaste gamme de sujets oculaires. L'Institut national canadien pour les aveugles (INCA) a le registre le plus compréhensif.
- Interprétation : L'étude est la première du genre cherchant à résumer l'information du secteur de la santé publique sur la cécité et la déficience visuelle au Canada. L'information oculaire actuelle fondée sur la démographie est déficiente. Une validation plus globale des données des grands registres, tel celui de l'INCA, sera nécessaire pour soutenir un système de surveillance oculaire longitudinale, qui pourrait guider la recherche sur les facteurs de risque et l'effet des traitements, les analyses économiques et l'élaboration de politiques sur la recherche oculaire et sur l'allocation des services.

T he spectrum of eye disease that has a significant effect on Canadians is enormous: from strabismus in infants to injury in young adults to diabetic retinopathy in middle age to macular degeneration in older people. However, the spectrum of information on the burden of ocular disease in Canada has not previously been well described. There have been no large population-based prevalence studies or surveillance systems of ocular disease in Canada. However, several health databases document information on blindness and visual impairment. Databases of this nature may permit studies of the outcomes, predictors, economic costs and meta-analysis of ocular health problems and visual disability in Canadians.¹

The purpose of this study was to comprehensively review three data sets — health administrative databases, health surveys and registries — relating to ocular disease and blindness in Canada. Whenever possible, we also evaluated the quality of the data, in terms of completeness, edit checks and whether reabstraction studies were done.

METHODS

We systematically identified ocular databases using the Polaris literature search engine and the MSN Webbased search engine. Key words used were "population health," "vision," "blindness," "health databases," "administrative databases," "health surveys" and "health registries." All searches were restricted to Canadian content only. After identifying all the databases, we obtained information on blindness and visual impairment in a staged procedure. First, any information available on the Web site or in the published literature was obtained. Second, the institution was notified by email or telephone that information pertaining to vision and blindness was desired. Finally, when necessary, we visited the institution to obtain the information.

RESULTS

Health administrative databases

In Canada, health administrative databases are of two main types: hospital abstracts (hospital admissions, discharges, diagnoses and treatments) and provincial medical claims databases (physician billings). Administrative and professional bodies require these data for hospital financing and evaluation.

Although the main purpose of administrative data is for hospitals to use in quality control and planning, these data increasingly are being used for research purposes.² In particular, they are used to study the epidemiology of disease, patterns of physician practice, and the relation between health care and outcomes.¹

Hospital abstracts

Hospitals are required to submit to administrative bodies abstracts of demographic and clinical information for all hospital discharges (inpatients) and for some outpatient visits. Demographic information includes the patient's age, sex and place of residence, and clinical information includes diagnoses and surgical procedures. The latter information is recorded with the use of the *International Classification of Diseases*, ninth revision (ICD-9),³ or the *ICD-9 Clinical Modification* (ICD-9-CM).⁴ Coders translate information from hospital charts, and the information is then entered into a database.

The Canadian Institute for Health Information (CIHI) is a leader in collecting and analysing information on health care in Canada. The CIHI maintains several databases containing information on health care services provided to inpatients and outpatients. Virtually all provinces, with the exception of Quebec, have mandated that hospital discharge records be submitted to the CIHI.

A description of the CIHI's health services databases is given in Table 1.⁵ The Hospital Morbidity Database contains the same information as the Discharge Abstract Database except that the former includes all acute care discharges for all the provinces and some long-term care facilities, and does not contain data on day surgery. The CIHI is working to combine the two databases. The institute maintains hospital morbidity data from fiscal year 1994–95 onward; data for previous years are maintained by Statistics Canada (Table 1⁶).

The CIHI recently started an Ambulatory Care Database. It will contain data on visits to the emergency department, outpatient clinics and day surgery. At present, only Alberta has mandated the collection of ambulatory care data. As most ophthalmic consultations and surgical procedures are performed on an outpatient basis, the Ambulatory Care Database would be very useful for health care services research in ophthalmology. However, as with the other CIHI health services databases, information from private clinics, where many ophthalmologists practise, would not be available.

The CIHI also maintains the National Physician Database, which has data on fee-for-service billings

aggregated at the physician and fee code level. The CIHI used the National Grouping System to standardize fee codes across the provinces.¹ The National Physician Database contains little information on ophthalmic assessments and surgical procedures. It could, however, enable comparison of cataract surgery rates for different geographic locations and the density of ophthalmologists in different areas.

The CIHI's information about the age, sex and residence of patients is generally complete and reliable. The institute returns abstracts with missing data to hospitals for editing. As a result, demographic information is missing in less than 1% of hospital abstracts.¹

Reabstraction studies of hospital records assess the agreement between the abstracted information in the database and the information in the chart that was recorded by the physician and then coded by hospital staff. There are no known reabstraction studies of records related to specific ophthalmic diagnoses or procedures. Other reabstraction studies have shown that demographic information is in general coded correctly, but clinical data on primary and secondary diagnoses vary in completeness and accuracy.¹ In Ontario's provincial reabstraction study the most responsible diagnosis in the chart agreed with that in the database in 81% of cases, yet agreement on additional diagnoses (coexisting conditions and complications) was very low (37%).¹

Provincial medical claims databases

Provincial medical claims databases capture physician services paid on a fee-for-service basis. Hence, information collected in claims databases covers people who have used the health care system, whether in hospital or in private clinics. When fee-for-service physicians bill for assessments and procedures, they submit claims statements to the provincial health insurance plan. In all provinces except New Brunswick, physicians must record diagnoses, using ICD-9 codes, on the claims statement in order to be paid for their services. Only four provinces (British Columbia, Alberta, Saskatchewan and Manitoba) have at least a minimal quality-control program in place.

Health surveys

Health surveys are usually conducted through an interview and sometimes by examination of a sample of the population. They are useful in determining the prevalence of conditions and many related

Table I—Health administrative databases containing information on blindness and visual impairment in Canada^{5,6}*

Name of database	·····		
or report	Contact	Information	Quality control
Discharge Abstract Database	Daria Parsons Canadian Institute for Health Information 200–377 Dalhousie St. Ottawa ON KIN 9N8 (613) 241-7860, ext. 3508	Database of hospital abstracts maintained by fiscal year Data elements: demographic information (sex, age, postal code); clinical information: diagnoses and ICD-9-CM codes, length of stay, admission	Several edits in place to ensure for quality assurance All diagnostic and procedural codes submitted are validated against the CIHI diagnosis and procedure codes
	Other contact: Christine Proietti, ext. 3513 cproietti@cihi.ca Web site: www.cihi.ca	Example of use: track all patients admitted to hospital with glaucoma, and the specific type of glaucoma Includes discharge data for inpatient acute care, chronic rehabilitation care and day surgery Database is not longitudinal; it cannot track individual patients Information from private clinics not available Provincial and territorial participation for inpatient data. British Columbia	
		Alberta, Saskatchewan, Ontario, New Brunswick, Nova Scotia, Newfoundland and the territories 100%; Prince Edward Island 85%; Manitoba 40%; Quebec 0% Provinces participating in day surgery program: British Columbia, Ontario, New Brunswick, Nova Scotia	
Hospital Morbidity Database	Sharon Kennedy Canadian Institute for Health Information 200–377 Dalhousie St. Ottawa ON KIN 9N8 (613) 241-7860, ext. 3532 skennedy@cihi.ca Other contact: Christine Proietti, ext. 3513 cproietti@cihi.ca Web site: www.cihi.ca	Same type of information as Discharge Abstract Database Includes all acute care discharges for all provinces and discharges from some long-term care facilities ICD-9-CM codes are used for diagnoses and procedures No data on day surgery or outpatient visits	Several edits in place to ensure for quality assurance Diagnostic and procedural codes are validated against the CIHI diagnosis and procedure codes Data are complete
Ambulatory Care Database	Micheline Mistruzzi Canadian Institute for Health Information 200–377 Dalhousie St. Ottawa ON KIN 9N8 (613) 241-7860, ext. 3252 mmistruzzi@cihi.ca Web site: www.cihi.ca	Will contain information for all hospital-based ambulatory care: emergency department visits, outpatient clinics and day surgery ICD-9 and ICD-9-CM coding systems are used Contains demographic information (date of birth, sex, postal code, residence code) admission/discharge information	Several edits in place to ensure for quality assurance All diagnostic and procedural codes submitted are validated against the CIHI diagnosis and procedure codes Data are complete
		(date and hour, type of admission), clinical information (service involved, physician, diagnoses, procedures)	continued

Table I—Con	Table I—Continued				
Name of database					
or report	Contact	Information	Quality control		
		Example of use: track specific procedures and surgical procedures done on outpatient basis in hospitals At present, only Alberta has mandated the collection of ambulatory care data; the CIHI has not received any data to date Information from private clinics would not be available			
Hospital Morbidity and Surgical Procedures ⁶ †	Circulation Management Statistics Canada 120 Parkdale Ave. Ottawa ON KIA 0T6 (613) 951-2800	Includes counts only for inpatient cases from general and allied special hospitals in Canada, excluding the territories Contains information on a few ocular	Validity edit checks that the necessary data elements are present and consistent, and eliminates extraneous elements (e.g., outpatient cases)		
	Web site: www.statcan.ca	conditions (glaucoma, cataract, strabismus and "other disorders of the eye and adnexa"): number of cases, age grouping, sex, province, average length of stay Contains same information for certain surgical operations (operations on lacrimal apparatus; operations on eyelids; operations on ocular muscles or tendons; operations on conjunctiva; operations on cornea; operations on iris, ciliary body, sclera and anterior chamber; extraction of lens; other operations on lens; operations on retina, choroid and vitreous)	Medical edit checks that reported diagnoses and procedures are reasonably consistent with reported age and sex		
National Physician Database	Marc Lalonde Canadian Institute for Health Information 200–377 Dalhousie St. Ottawa ON KIN 9N8 (613) 241-7860 mlalonde@cihi.ca Web site: www.cihi.ca	Data on the sociodemographic and billing patterns of fee-for-service physicians, as well as age and sex of patient, beginning from fiscal year 1989–90 Fee codes across provinces are standardized using National Grouping System Information on the number of physicians, population per physician, and physician:population ratios is also available No information on diagnoses	Quality control is carried out by provincial health insurance plans At the CIHI various edits are in place for creating the reports		

†Existed before 1993–94 as two separate reports (Hospital Morbidity and Surgical Procedures and Treatments). The information in Hospital Morbidity and Surgical Procedures is identical to that in the two former reports.

socioeconomic factors in a population, including people who are not necessarily in contact with the health care system.⁷ Often, outside investigators are encouraged to perform further analyses, by purchasing an analysis tape for the survey that includes any specified set variables.² Table 2 provides an overview of large population-based health surveys that contain comprehensive data for disabled people and information on the burden of blindness and visual impairment in Canada.⁸⁻¹⁰

Table 2—Health surveys containing information on blindness and visual impairment in Canada ^{8–10}				
Name of survey	Purpose	Sample size (for household survey)	Sampling scheme	Method of data collection
National Population Health Survey, 1996–97	Longitudinal survey to measure the health status of Canadians; focus on the use of health care services	58 439	Cluster sampling	Telephone interviews conducted using computer- assisted interviewing Data captured by Statistics Canada regional offices and then transmitted to Statistics Canada headquarters
National Population Health Survey, 1994–95	Longitudinal survey to measure the health status of Canadians; focus on health status	58 439	Cluster sampling	In-person interviews conducted using computer- assisted interviewing Data captured by Statistics Canada regional offices and then transmitted to Statistics Canada bodduartees
Health and Activity Limitation Survey, 1991	To build a national database on disability	148 000	Simple random sampling	In-person or telephone interviews conducted Data captured by Statistics Canada regional offices and then transmitted to Statistics Canada headquarters In-person or telephone
Health and Activity Limitation Survey, 1986	To build a national database on disability	184 500	Simple random sampling	interviews conducted Data captured by Statistics Canada regional offices and then transmitted to Statistics Canada headquarters

National Population Health Survey

Statistics Canada's National Population Health Survey (NPHS) is a longitudinal survey designed to measure the health status of Canadians. Data collection began in June 1994 and has continued every second year thereafter. Most of the information is collected by interviewing a single household member.⁸ Data for the 1996–97 cycle were available in early fall of 1998. The 1994–95 NPHS focused on the health status of Canadians and on the use of health care services. There were a limited number of questions on ocular health (e.g., use of corrective lenses, cataracts and glaucoma). Based on self-reports of Canadians aged 18 years or more, there are about 580 605 people with cataract and 233 575 people with glaucoma, as diagnosed by a health care professional. The data files allow access to crosstabulations; thus, data can be aggregated by age and by sex. Data for 1994–95 indicated that the prevalence of cataract in older people living in private households was 13.9% (17.3% for women and 9.4% for men).¹¹

Health and Activity Limitation Survey

Statistics Canada's Health and Activity Limitation Survey⁹ (HALS) collected data on the nature and

severity of disabilities, the need for and use of assistive devices, the barriers faced by people with disabilities and the out-of-pocket expenses related to disability. The HALS was first conducted after the 1986 population census and was repeated after the 1991 census. Two questions on activity limitation and long-term disability appeared on the Long Census Questionnaire, which was distributed to 20% of Canadian households and used to identify the target population. Interviews were conducted with people who responded "Yes" to the two census questions. The response rate for the household survey was 90% in 1986 and 87% in 1991.

The proportion of adults with vision disabilities decreased from 16% in 1986 to 14% in 1991, but the actual numbers increased (from 445 875 to 510 755). Other data from the surveys show that in 1991, 24.1% (298 370) of older people with disabilities had visual disabilities, compared with 23.5% (241 515) in 1986.¹¹ Among children under 15 years of age with disabilities, 8% (30 240) had visual disabilities in 1991, compared with 10% (27 770) in 1986.¹¹

Registries

Registries typically are government-supported agencies that collect statistics for certain chronic diseases, especially cancer. There are several registries that contain information on the ocular health of Canadians (Table 3). The registries that we describe collect a wide range of data, from characteristics about blind people to sports-related causes of eye injuries. Registries are an important source of information because if they are well kept, they can provide data on the incidence and prevalence of diseases.⁷

Canadian National Institute for the Blind

The Canadian National Institute for the Blind (CNIB) has been in existence since 1918.¹² Its mandate is to ameliorate the quality of life of visually handicapped people and to prevent blindness. The CNIB provides services not only to legally blind people but also to those with any level of visual impairment. An annual pamphlet prepared by the CNIB, *CNIB Client Statistics*,¹² contains statistics for people entered in the CNIB database, regardless of their degree of visual impairment. People can be referred to the CNIB by their ophthalmologist or optometrist, and also by self-referral. The CNIB also maintains a client database, which contains information about CNIB clients, including the percentage distribution of clients by vision level.

Dr. Tom Pashby Sports Safety Fund

The Dr. Tom Pashby Sports Safety Fund maintains a registry on eye injuries and blinded eyes in Canadian sports. Dr. Pashby has been working to protect athletes from eye injuries for over 25 years. Statistics on sports-related eye injuries and blinded eyes come from the Canadian Ophthalmological Society Sports Eye Injury Survey.¹³ This questionnaire is mailed to every ophthalmologist in the country. Ophthalmologists are encouraged to fill out the questionnaire; the response rates have not been documented (Dr. Tom Pashby: personal communication, 1999).

National Cancer Institute of Canada

The main purpose of publishing data from cancer registries is to provide health care professionals, researchers and policy-makers with detailed information about the incidence and death rates of the most common types of cancer by age, sex, period and province. The National Cancer Institute of Canada, in collaboration with Statistics Canada, Health Canada, and provincial and territorial cancer registries, began publishing Canadian Cancer Statistics¹⁴ in 1987. Current editions of this publication are available on the Internet. Information on the incidence of cancers and associated death rates comes from the provincial and territorial cancer registries and offices of vital statistics, which submit their data to Statistics Canada for compilation at the national level. In contrast to the information given for relatively more common cancers, there is no information on estimates of death from ocular neoplasia by sex and by province for the current year, the lifetime probability of acquiring and dying from ocular neoplasia, or the potential years of life lost due to cancer of the eye. One of the main limitations of using national cancer data is the considerable delay before the information becomes available.

Canadian Institute for Health Information eye injury registries

The CIHI maintains two important registries that contain information on eye injuries: the Ontario Trauma Reports and the National Trauma Registry Reports.⁵ These registries contain information on the number and causes of ocular injury submitted by all acute care hospitals in Ontario and Canada respectively. Г

Name of registry	Purpose	Method of data collection	Information	Quality control
Canadian National Institute for the Blind Web site: www.cnib.org	To document the reasons for blindness in Canada	Descriptive: counts used Volunteer information provided by ophthalmologists, optometrists and self- reporting people in all provinces	CNIB Client Statistics contains data on the causes of blindness and visual impairment	None known
Dr. Tom Pashby Sports Safety Fund Web site: www.drpashby.ca	To document the number of sports- related eye injuries and the number of eyes blinded in sports and recreational activities	Descriptive: counts used Canadian Ophthalmological Society Sports Eye Injury Survey voluntarily submitted by Canadian ophthalmologists	Sport-specific number of eye injuries and blinded eyes	None known
National Cancer Institute of Canada Web site: www.ncic.cancer. ca	To provide detailed information on incidence and death rates for cancer, including cancer of the eye (ICD-9 code 190) and retinoblastoma	Descriptive: counts used Provincial and territorial cancer registries and offices of vital statistics document cancer cases and send data to Statistics Canada for compilation	Ocular neoplasia	None known
Ontario Trauma Reports, Canadian Institute for Health Information Web site: www.cihi.ca	To build a provincial database on injuries, including eye injuries	Descriptive: counts used All acute care hospital admissions due to injury in Ontario are coded according to the ICD-9 or ICD-9-CM coding systems and submitted to the CIHI	Demographic (age, sex, postal code) and clinical (ICD-9 codes) information for all acute care hospital admissions due to injury in Ontario No existing report available on eye injuries, but it would be possible to create a report detailing the number and causes of eye injuries	Several registry- specific quality- control initiatives in place
National Trauma Registry Reports, Canadian Institute for Health Information Web site: www.cihi.ca	To build a national database on injuries, including eye injuries	Descriptive: counts used All acute care hospital admissions due to injury in Canada are coded according to the ICD-9 or ICD-9-CM coding systems and submitted to the CIHI	Demographic (age, sex, postal code) and clinical (ICD-9 codes) information for all acute care hospital admissions due to injury in Canada No existing report available on eye injuries, but it would be possible to create a report detailing the number and causes of eye injuries	Several registry- specific quality- control initiatives in place continued

The registries contain demographic and clinical information (ICD-9 codes) on cases of eye injury. However, at present, there are no reports detailing the number and causes of eye injuries.

Canadian Hospitals Injury Reporting and Prevention Program

The Canadian Hospitals Injury Reporting and Pre-

Table 3—Continued				
Name of registry	Purpose	Method of data collection	Information	Quality control
Canadian Hospitals Injury Reporting and Prevention Program (CHIRPP), Health Canada Web site: www. healthcanada.ca	To provide summary reports on injury occurrence as well as information for more detailed research; also has preinjury information Primary focus is on children and youth aged 19 years or less	Descriptive: counts used Computerized information system collects and analyses data on injuries and poisonings from emergency departments A total of 16 hospitals (10 pediatric, 6 general) report injuries Patient or accompanying adult fills out a one-page questionnaire about the injury incident Attending physician provides details on the nature of the injury CHIRPP coordinator submits CHIRPP forms to Child Injury Division, where they are entered into CHIRPP database	Demographic (age, sex, postal code) and clinical information for admissions due to injury in selected hospitals in Canada Patient questionnaire provides information on the circumstances surrounding the injury (what the child was doing, what caused the injury, the factors contributing to the injury, time and place injury occurred) Physician's summary details the nature of the injury (e.g., eye injury), whether intent was involved and the	Some charts are randomly chosen and double- checked to ensure continued information was entered correctly into computer Program checks prohibit invalid and illogical entries
National Work Injuries Statistics Program, Statistics Canada	To detail statistics on work-related injury and illness	Descriptive: counts used Claims of time-loss injuries received from provincial workers' compensation boards	Data on the total number of accepted time-loss injuries of the eye, by province and by industry division	None known
Selected notifiable diseases, Statistics Canada Web site: www.statcan.ca	To document the number of cases of selected notifiable diseases	Descriptive: counts used Reporting by hospitals	Typically infectious diseases	None known

vention Program (CHIRPP) is a program of the Child Injury Division, Centre for Chronic Disease Prevention and Control, Health Canada. CHIRPP was established in 1990 to collect data on injury occurrence and circumstances surrounding injuries in children and youth. Currently the program collects and analyses data on injuries from emergency departments in 16 hospitals (10 children's and 6 general) across Canada.¹⁵ The CHIRPP database has been used by investigators to obtain information on eye injuries. Marshall and colleagues¹⁹ used CHIRPP data to determine the number of eye injuries from air guns, the severity of the injuries, how the injuries occurred and the demographic features of the patients. An advantage of the CHIRPP database is that data are available within 2 to 4 months of the injury. A limitation of CHIRPP data is that a considerable proportion of injuries in Canada are not captured in the database. For example, no hospital in Saskatchewan and only one hospital in Alberta (Alberta Children's Hospital, Calgary) reports injuries to CHIRPP.

National Work Injuries Statistics Program

The National Work Injuries Statistics Program was established by Statistics Canada and the Association of Workers' Compensation Boards of Canada to detail statistics on work-related injury and illness. The program uses claims records of workers' compensation boards and commissions for statistical purposes.¹⁶ The data on work-related eye injuries include only cases of eye injuries that have been accepted as claims by workers' compensation boards. Information on eye injuries includes the number of accepted time-loss injuries among injuries to the eye by province and by industry division. More detailed information on the type and severity of eye injuries can be obtained from the provincial workers' compensation boards. Data on work-related eye injuries are important for observing trends in eye injuries.

Notifiable diseases

Statistics Canada's data on notifiable diseases¹⁷ are derived from health administrative databases. Notifiable diseases typically are infectious diseases that public health officers have declared must be reported.

INTERPRETATION

In this paper we present a comprehensive review of the databases that contain information on the ocular health of Canadians. Most of these data sets are computerized databases that are publicly available. Given that the demographic characteristics of the population will change quickly over the next 20 years, it will be important to have an accurate profile of the burden of blindness and visual impairment in Canada. This will enable us to evaluate the effectiveness of eye care provided to Canadians and to stress the importance of prevention.

Health administrative databases, hospital abstracts and provincial medical claims databases attempt to maintain reliable and complete data. Increasingly, they are being used for studying the epidemiologic features of disease. Although the demographic information they contain is accurate, they have important limitations with respect to their use in visual health and disease research and policy making. The CIHI maintains several health services databases, but the focus of these databases is on inpatients, a huge limitation in ophthalmology. With provincial medical claims databases there is little quality assurance of diagnostic codes. Even when the data are correct, they simply provide a cross-sectional "snapshot" of one diagnosis for a patient at any one time; any use of diagnostic codes as a function of time is not possible. Furthermore, the diagnostic code may be biased by the necessity to justify the medical act. In summary, health administrative databases may have a promising role in determining the burden of certain eye diseases and may link some diseases with demographic features cross-sectionally, but their role in research and policy decisions in eye care, particularly on a longitudinal basis, is very limited.

The most recent large population-based health surveys in Canada, Statistics Canada's NPHS and HALS, have the advantage of being well representative of the population. Like most health surveys, however, the NPHS and HALS have limitations. First, there is a degree of subjectivity in the definition of "seeing disability." The surveys were based on self-reports from respondents, and no eye examinations were conducted. In the report Blindness and Visual Impairment in Can ada^{18} the cause of vision limitation was reported in very vague categories: "is a disease," "aging," "caused by a disease" or "birth." For a clearer picture on the cause of visual impairment, perhaps more specific questions could have been asked. Another limitation of the surveys is that no eye examinations were conducted. The perceived vision status was based on self-reports. In addition, surveys pose numerous methodologic problems. Respondents have been shown to forget even major events in their lives, and if the interviewer is not trained properly, he or she can influence the depth and quality of the responses.⁷ Elliott and associates²⁰ showed that, in surveys, low-vision needs may be overreported for adults aged 15 to 64 years but underreported for older people.

Registries are an important source of data to track the occurrence of diseases and conditions in a given area. The CNIB maintains the most comprehensive data on blindness and visual impairment in Canada. With the addition of several new registries (Ontario Trauma Reports, National Trauma Registry Reports and CHIRPP), there is now a large array of data available on eye injuries.

One of the main limitations of most Canadian registries on visual impairment is their lack of independent validation. This step is crucial even for fairly comprehensive registries, such as the CNIB database, if the ultimate step in blindness prevention is to take place: the creation of a national surveillance system. Validation may begin at the local or regional level (and we have begun the process in Ontario), but ultimately a national validation system would be the major goal. Then the existing infrastructure of administrative databases, surveys and especially registries could be used to create a longitudinal surveillance system of vision loss in this country. Such a system would track the main reasons for vision loss, both overall and stratified by geographic, social and cultural factors. Large population needs and even regional patient needs could be assessed, and the proportion of research and service dollars that should be allocated to basic research, clinical research and population health issues could be determined. Economic analysis of visual loss as well as optimization of service provision would be the logical extensions. Our review shows that we as a nation are far from attaining these goals. It is hoped that future resources will be allocated to meet these needs.

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Key words: blindness, visual impairment, eye diseases, eye injuries, public health, databases, health administration, surveillance

Discussion

T he authors of this study present an extensive listing of sources of information that may have relevance to researchers or policy makers interested in eye disease in Canada. If existing databases are to be used for future epidemiologic or economic evaluations, careful scrutiny of the quality and usefulness of existing sources of information is warranted. This review provides a very complete documentation of eye disease information resources in this country and underlines the generally poor state of database information that is available.

Provincial and national medical databases may provide ophthalmologists an overview of the burden of eye disease in Canada; these databases may also offer a better understanding of the flow of patients with eye disease through our health care system. However, most of the existing databases were created for purposes other than the evaluation of eye disease. For this reason, a single database is unlikely to provide all the information required to answer specific ophthalmic research questions. In the future, the computerized linking of databases may provide answers to some research questions that are specific to ophthalmology. One of the successes of the paper by Tahir Hameed and colleagues is the documentation of background information on existing databases for those considering linked database research into eye disease.

Although linkages can be useful, there are significant limitations to this research technique. First, database linkages do not answer many types of research questions well, especially those evaluating outcomes or diseases managed on an outpatient basis. Second, as noted by the authors, most of the databases reviewed have fundamental flaws, often in data quality or completeness, which limit the strength of conclusions that can be drawn from their use in single database or linked studies. Third, privacy and ethical issues surround the identification of individuals or groups on the basis of race, disability or disease status, thereby often restricting what information can be abstracted and studied. Fourth, even with newer computers, database linkages can result in massive data sets that are not easily manipulated in the absence of very skilled computer operators.

Given these limitations, research using existing data sets should be considered primarily for disease surveillance. Surveillance is the process of tracking disease trends within populations — typically for directing policy decisions — and may identify irregularities within a population's health status that can subsequently be more thoroughly investigated by other research methods.

The National Diabetes Surveillance System (NDSS) is a good example of a national database linkage that brings together hospital and medical service databases. The goal of this project is to provide an ongoing, systematic database linkage that allows for the analysis and dissemination of information on the burden of diabetes and its risk factors. With \$12 million of funding and over 5 years of organization, the NDSS is still in its early stages of implementation. There have been hurdles to the process, and the results, so far, are limited to incidence data and cost evaluations that are more useful for policy makers.

The ophthalmic community in Canada is unlikely to find the resources required to establish a similar database project. Even if such resources were available, the NDSS experience and the findings of the present paper suggest that existing databases on eye disease in Canada would not be able to provide much in the way of outcome or risk factor data. Would the benefits of general surveillance data on eye disease be worth the very high costs?

Considering the complexities and limitations of a national surveillance system for eye disease, what options are available in the short term for increasing our knowledge about eye disease in Canada? Certainly, efforts are needed to better understand the burden of eye disease regionally and nationally and to increase public and political awareness of eye care needs. Moreover, Canadian data on risk factors and treatment outcomes for eye disease would be welcomed by most in our profession.

One possible approach lies in directing resources toward some population-based studies that could be undertaken at the regional level. Alternatively, smaller, cost-effective province- or region-based database linkages could be performed in conjunction with university departments or organizations that have established relationships with the managers of provincial hospital and medical service databases. Examples of such efforts already exist within the Canadian ophthalmic literature — for cataract¹ and diabetic retinopathy² — and appear to have been an efficient way of providing policy-oriented data.

Another fruitful approach would be to improve existing ophthalmic databases. The efforts of the Canadian National Institute for the Blind to develop a more comprehensive client database are a positive step. Linking this new database with physician billing data, for example, may have some value for tracking the costs of blindness related to various eye diseases. Similar efforts are under way to develop a new national ocular trauma registry. If successful, a more comprehensive picture of eye injury will become available.

Canada can learn from foreign ophthalmic databases. Sweden has an excellent example of a national registry for eye disease. The national retinal detachment registry, run out of Linköping, is an Internet-based project that has been able to capture information on over 75% of the nation's retinal operations over the past 5 years. A total of 270 different pieces of information are collected for each patient during the course of retinal care. This project has generated very interesting outcome and risk factor data that would not have been possible otherwise.

The authors of this study are to be congratulated on their comprehensive review of present databases for the evaluation of eye disease in Canada. Although the poor quality of existing databases renders many applications of these data problematic, general costing and prevalence research may be possible. Such information is likely to be invaluable in raising the profile of eye disease nationally and helping to establish goodquality, ophthalmology-specific databases in the future.

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