

## **Federal Injury Surveillance in Canada: Filling the Gaps**

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### **Abstract**

Health Canada's experience in injury epidemiology was almost nonexistent when, in May, 1989, representations to the Deputy Minister resulted in the formation of a 10-hospital surveillance system for childhood injury on a three year pilot basis. The first of the three years was devoted to investigating injury surveillance systems around the world for philosophical and technical merit and negotiating a working arrangement with the 10 Canadian pediatric hospitals. Eleven months later, in April, 1990, the first data from the *Children's Hospitals Injury Reporting and Prevention Program* (CHIRPP) were generated.

CHIRPP was based on the Australian national injury surveillance program (NISPP) and although a number of modifications have been made in both programs over the last four years they continue to share almost identical data collection strategies and record content. Both are Emergency Room-based systems which emphasize pre-injury event circumstances, as small a response burden on data providers as possible, a rapid processing turnaround for timeliness and a powerful software interface which is given to all program participants.

CHIRPP is now the *Canadian Hospitals... Program* because it now includes five general hospitals and has become, by default, an all-ages surveillance program although the emphasis remains on children. The presentation will concentrate on the strengths of the ER-based approach, some of the major difficulties that have been encountered and the usefulness of the program in the spectrum of activities that comprise injury surveillance and control.

### **Data Sources Prior to CHIRPP**

Canada is a federal nation consisting of ten provinces and three territorial areas, each having its own government and a federal government, based in Ottawa. Provincial governments are responsible for the collection and maintenance of Vital Records and for the provision of direct health care services. Therefore, certain population-based information on "health" in a broad sense and on injury in particular are collected and collated at the provincial/territorial level, e.g., death certificates, hospital admission/discharge records. Under fairly long-standing and stable arrangements, copies (or in some cases, summaries) of these records are sent to the national statistical agency, Statistics Canada, for pooling into national datasets. For example, the national Mortality Database exists in machine-readable form back to 1950 (1927 for some provinces) and the national Hospital Morbidity Database dates back to 1979.

Both of these files are based on individual records (although person-based in the case of mortality and event-based in the case of morbidity) and both have been used by researchers and policy makers attempting to either summarize secular trend in injury occurrence, identify emerging injury hazards, carry out risk analysis-type exercises and even to attempt to monitor the effect of injury intervention programs.

Although neither dataset has been used to its full potential, these morbidity and mortality files have formed the basis for almost all of the injury epidemiology and prevention work that has been done in Canada when such activities have been "data driven".

There are two problems with this approach; one bears directly on my presentation today and the other only tangentially. The former has to do with the fact that hospitalization and death from injury, as important as they are, represent a relatively small proportion of the number of injuries that occur, i.e., the most serious or severe part. But this is a "clinical" or "medical" use of the term "serious", not a public health use. Injuries that are catastrophic (and possibly costly) to individuals tend not to be those that place the largest burden on populations. Concentrating on hospital admission and death from injuries reinforces the notion that the individual, "big injury" is the proper societal

focus and this continues, in general, to be the case. It is also the case that the information on these records concentrates on post-event, patient management data.

The other problem is a constellation of difficulties and shortcomings created by historical inertia, logistics and bureaucratic compromises. Both hospital in-patient and mortality records are completed well after the injury event and sometimes, particularly in the case of mortality records, so long after that the event is not related to the outcome. Both record systems are primarily administrative in nature and contain little covariate information. Both are coded to the ICD revision of the day, the deficiencies of which for injury prevention planning purposes have been widely documented.<sup>1</sup> Both record systems concentrate on post-event, patient management and outcome data and are virtually lacking in any circumstantial information that might prove useful in planning interventions. Neither dataset is available less than two years from the date of the event and access is controlled by the provisions of the national *Statistics Act* and the cost-recovery mechanisms of Statistics Canada. The hospital in-patient records are not as yet linked to form records on individuals. The fact that these are *events* and not persons is a handicap to their usefulness.

In brief, mortality and hospital in-patient records provide a fairly selective window on injury in the population in a not particularly timely, informative or accessible way. They have been used to some advantage in the past and will continue to play a role in the development of our knowledge about injury but present sufficient shortcomings to predict a need for supplementary data sources.

### **Filling the Gap**

Such a need was expressed by a group of professionals interested in injury prevention who met in 1988. Dr. Barry Pless of McGill University and one of Canada's few *bona fide* injury epidemiologists represented this group in meetings with Dr. Maureen Law, then Deputy Minister of Health Canada (at that time known as Health and Welfare Canada). One of Dr. Pless' messages was that Health Canada had a responsibility to conduct injury surveillance. His detailed arguments must have been unusually compelling and it was decided that the department would attempt to conduct a three-year pilot surveillance program in the ten Pediatric Hospitals in Canada. That was about the extent of the instruction I received five years ago in May, 1989.

We were generally aware of the limitations of mortality and in-patient morbidity records as a source of surveillance data. After a rather hurried review of some existing injury surveillance programs around the world we were put in touch with officials of the Australian national program which is now known as NISPP. The Australian program, although fairly recently established at that time, was attractive philosophically, technically proven and available. After an exchange of letters at the Ministerial level the software arrived from Australia, *gratis*. This software formed the basis for what is presently called the *Canadian Hospitals Injury Reporting and Prevention Program* (CHIRPP). Although the software itself has undergone several fundamental modifications in the interim and the organization of the national programs in Australia and Canada have developed along different lines, the NISPP ancestry of CHIRPP is easily seen and gratefully acknowledged.

### **Goals and Philosophy of CHIRPP**

The primary tenet underlying CHIRPP is that many, if not most, injuries are preventable or can be minimized by the use of appropriate strategies.

By placing within communities collections of data acquired from surveillance in that same community and encouraging the community to use those data to develop and test intervention exercises is potentially the most cost-effective way of developing strategies to make the Canadian environment safer.

By doing this in multiple, dispersed and disparate locations, studies can be undertaken to identify the influence of factors unique to individual communities and the differing degrees of influence of common factors in different environments.

By maintaining a centralized national collection studies can be undertaken to identify population-wide influences and influences specific to age, gender, neighborhood, cultural background, emerging hazards from newly-introduced consumer products of all kinds and other factors.

CHIRPP is unique in that it is the only injury surveillance system in the world which contains cause and effect information on each of the accident and the injury components, precoded and available to the user by direct inquiry.

CHIRPP is designed to provide timely data. It is designed to operate effectively in the "real world" where data collection and completion rates fall below theoretically optimal targets and where significant but varying proportions of the data collected can be largely anecdotal. It is designed to allow non-specialist users separate important signals from noise in an environment where coding mistakes and diagnostic errors actually happen. In short, CHIRPP is designed, because the Australian concept allowed it, to be simple, cost-effective and useful.

## **Operational Details**

### Background

In somewhat more technical terms, CHIRPP is a hospital-based sentinel surveillance system. It is an "active" surveillance system in the sense that individuals are sought out (in the Emergency Room) and data are collected on a purpose-designed form, not abstracted from a form designed for a different purpose.

Participating hospitals are supplied with an IBM-compatible PC, the CHIRPP software and all relevant licences, data collection forms and funds, contracted on an annual basis to cover costs of long-distance telephone calls, hardware maintenance and the salary of a program coordinator based on a formula which incorporates a flat rate plus additional remuneration based on the number of records collected. The intention is to defray costs of the program to the hospital to the greatest extent possible. This is done at the price of accommodating more centers with a less generous compensation scheme or allowing more than one type of "membership" in the program.

Each hospital has a CHIRPP "Director" who is usually the Director of the Emergency Service. The Director, who is not personally compensated in any way, is the real "sponsor" of the program in each hospital and is expected to generate and foster enthusiasm for and acceptance of CHIRPP. Directors are also supposed to encourage the use of CHIRPP data locally both within and outside of the hospital.

Completed data forms are submitted to the national office at regular intervals for coding and keying. After keying, a copy of the electronic version of the records is returned to the hospital of origin to be merged into the local database. All records are also merged into the national dataset in Ottawa. All participating centers and the national office use exactly the same software.

### Data Collection

The face of the data form is self-administered, i.e., it is completed either by the injured person or by a responsible person in attendance. In the case of children, this is usually a parent. The reverse of the form is supposed to be completed by the attending physician.

This data collection strategy has the great advantage of placing a minimum of responsibility on hospital staff but it requires a population literate in one of the two official languages. This requirement is a concern in the inner cores of some cities which have experienced heavy in-migration in recent years of peoples lacking language facility in either English or French. Moreover, about 10% of people receiving a form refuse to complete it. We have not as

yet studied their characteristics but assume they are not "typical" of the general population of those who attend Emergency Rooms.

We have experienced considerably more difficulty with physician compliance. Although the reverse of the form should take no longer than 10–15 seconds to complete by someone who has seen it a few times, staff meetings, Grand Rounds, including the CHIRPP form in the Emergency Room chart and even the prospect of payment per form completed has proven to be insufficient incentive to achieve satisfactory physician compliance. In fact, most coordinators spend a good deal of their time completing the reverse of the CHIRPP form from details in the chart. This is not difficult but it is time consuming and it is not what we consider the best use of the coordinator's time.

Naturally, not all forms are completed equally. One wishes that everyone would fill all available space with clear, cogent, narrative done in 8–point Letter Gothic *sans serif*. That this is not the case can hardly be surprising. The fact that the amount of description varies from hospital to hospital might be. Nevertheless, the amount and richness of information that is passed on is impressive. An important part of the Coordinator's job is to ensure that the data capture rates and the quality of what is reported are as high as possible.

### Data Coding, Key punching

CHIRPP started with coding and key punching done at the local level. This was abandoned after three years. One of the most difficult features of the Australian approach is in the attempt to summarize, in a few codes, the reasons why the injury occurred (i.e., the so-called "Breakdown" factors). This is a complex concept to impart, requiring, as we came to realize, intensive training and regular in–service refreshers. With (originally) 10 (now 15) hospitals scattered over a 4,800 km distance and 5 time zones we were simply not able to maintain the necessary contact with the coders.

Data forms are now coded and keyed in the national office by four full–time staff who work together, teaching and learning from each other. Coding consistency has increased considerably and the cost per record for data entry has decreased marginally. Approximately 2,400 records are processed and added to the national database each week.

### Data Use

A surveillance system that is not used is useless. In the risk assessment/risk management model, surveillance data can and should be used at many points including hazard identification, risk estimation, option development and monitoring/evaluation.

CHIRPP data have not yet been used at either or local or national level to the extent originally anticipated. The program has been more or less preoccupied until the last year with collecting and coding data. However, analysis and dissemination activities have increased lately and are, of course, encouraged.

The federal–local nature of CHIRPP is somewhat unusual and it has taken two years of work to forge meaningful working relationships with the myriad of federal, provincial and non–governmental agencies with an interest in injury prevention which have appeared in the last five years. The direct application of CHIRPP data at the local level for program planning with subsequent program evaluation via CHIRPP has yet to happen but we are working toward it.

### Program Management

Apart from four full–time data coders, CHIRPP is administered in the national office by a Section Head (Ph.D. in Epidemiology), an analyst (M.Sc. in Epidemiology), a Research Assistant and an Information Officer for communications functions. An additional analyst position is currently vacant. There is no in–house computer hardware or software support; it is contracted–in.

A consultative committee composed of professionals from a variety of disciplines and organizations was formed two years ago and meets twice a year to review the problems, progress and plans (including budget) of the program. In addition, the national office brings the CHIRPP Directors once a year for review and planning and brings the Coordinators together to compare notes on what works (and doesn't work) in each centre to improve data capture and quality. All of these meetings generate minutes with action items which are taken seriously and followed up.

The available staff complement seems about right to handle a program the size and design of CHIRPP as does the amount of contact we have with our consultative committee. The program would probably benefit from somewhat more frequent contact between and among CHIRPP Directors, Coordinators and national office staff but the distances and competing make this difficult.

### **Has the Gap Been Filled?**

In the last five years CHIRPP has had its share of misplaced compliments and criticisms. It has been criticized for not being population-based when in fact it was never intended to be. It has been criticized for not "getting the message" out with some justification although that is now happening. It has been complimented as a technical marvel although we basically owe it to the Australians.

The important point is that the program seems to be working. Surveillance is more a psychological, sociological and diplomatic undertaking than a technical one and progress in the beginning is incremental. Nevertheless, a body of data is starting to emerge of a richness and detail that simply does not exist anywhere else in the country or the continent. The obverse is that this richness of self-reported human experience is "fuzzy" and a lot of data is necessary to extract the important information it contains.

CHIRPP is designed to make possible the extraction and interpretation of meaningful information by any reasonably educated person. Specialized subject-area knowledge is not a prerequisite. The potential exists to easily train large numbers of people to become CHIRPP data users at minimal cost. This potential encourages the formation of community-based, intersectoral injury prevention action groups which use CHIRPP data both to determine their goals and priorities and to evaluate their own intervention initiatives. CHIRPP is designed to encourage local experimentation. These will, individually, be data driven, tentative and inexpensive. Many will not succeed but knowing what doesn't work should be regarded as being of equivalent importance as knowing what did. Those programs that do succeed (as proven by the ongoing CHIRPP surveillance) can then be evaluated for national application. Little money will be spent in the experimentation overall and the potential for reducing costs of health care (including rehabilitation) and productivity due to potential years of life lost is considerable.

### **Reference**

1. Langley, JD. (1982) The International Classification of Disease Codes for Describing Injuries and Circumstances Surrounding Injuries: A critical comment and suggestions for improvement. *Accident Analysis and Prevention* 14:195-197.