

DEVELOPMENT OF A NATIONAL RECORD LINKAGE PROGRAM IN CANADA

Martha E. Smith, Statistics Canada

This paper briefly outlines the development of a national record linkage program in Canada and its current and anticipated future impact on epidemiological research. Opportunities are described for improved assessment of occupational and environmental health problems: (a) by exploiting existing administrative data files for statistical purposes; (b) by applying newer methods of organizing microdata files that facilitate computerized searching and integration of these fields into the form of individual linear histories of events and circumstances in the lives of people; and (c) by the application of probabilistic computerized record linkage techniques.

1. EXPLOITING EXISTING DATA FILES

Administrative records may serve different functions in the follow-up process. They may identify an individual as belonging to an 'exposed' or 'at risk' population (or to a 'control' population with which the other is to be compared). In this case, they may be referred to as 'starting point' records which initiate the follow-up process. Alternatively, they may identify an end effect, such as cancer or death, in an individual who is a member of a study population, in which case they may be referred to as 'endpoint' records. Follow-up will thus consist of using a file of starting-point records to search a file of potential endpoint records, and of linking those which relate to the same individual.

Particular emphasis will be on the endpoint record files being developed at Statistics Canada, the follow-up procedures used, and the starting point records currently available. The growing demand for such statistical data will undoubtedly result in improvements to the starting point and endpoint data sources as they become increasingly used in the future.

2. DEATH AND CANCER AS SPECIAL INTEREST ENDPOINTS

Statistics Canada must maintain an awareness of potential requirements for national health data which may be met by Statistics Canada initiatives. Most public concern over industrially and environmentally caused ills has to do with effects on mortality, such as cancer and cardiovascular disease, and on the incidence of cancer in individuals who do not necessarily die from it. Our emphasis to date, therefore, has been on the organization of endpoint files of death and cancer records required to do long-term follow-up on a national scale, because this is a function which other institutions are unable to perform due to the confidentiality laws governing the use of such information. Outside institutions generally come to us with detailed starting point records which relate to some specific group under study. We often carry out the necessary file searches and tabulations on a cost-recovery basis. The statistical analyses and the interpretations of the results are often done by outside organizations, such as the National Cancer Institute of Canada, federal and provincial health or labour departments, and universities.

The Mortality Data Base is one such endpoint file which has been organized using historical machine-readable records. Although information pertaining to all Canadian death registrations has been routinely entered into machine-readable form in a relatively uniform fashion for several decades, the files have not until recently been readily searchable. The Mortality Data Base is now maintained in three forms.

The first consists of magnetic tapes with coded cause of death for over four million events, for the period 1950-79. This file is basically in a standard format, consolidated over all Canadian provinces, and over spans of years to facilitate searching by computer.

The second form of the Mortality Data Base consists of compact microfiche containing an alphabetic listing of deaths dating back to 1926. These fiche are used manually for small research studies. Two additional sets of microfiche have been created from 1950 onward which are sorted in alternative sequences, one by death date and the other by death registration number.

The third form of this base is a historical summary file which has been created to meet special requirements for historical tabulations. A typical use of such a file is the production of mortality atlas data to demonstrate the geographic variations of death rates in Canada, so as to facilitate the identification of high risk regions and any general patterns of disease distribution [1-2].

The National Cancer Incidence Reporting System is the second of the two major data bases used for follow-up. It has been in operation since 1969, and is based on reports from nine provincial cancer registries. Less experience to date has been gained with the use of this file for long-term follow-up.

3. THE RECORD LINKAGE SYSTEM

A Generalized Iterative Record Linkage System (GIRLS) has been developed to efficiently carry out the probabilistic matching of data files, and to do so easily for a wide variety of research requests. This system was developed in collaboration with the Epidemiology Unit of the National Cancer Institute of Canada and has been described in detail earlier [3-4]. Some of the major features of the system are that it operates either in batch or on-line mode, it is modular in development, and it utilizes weights to produce a quantitative measure of the total probability that two records being compared do or do not relate to the same entity. The particular rules used in the linkage are variously tailored to the starting point files coming to us from a wide variety of research investigators.

GIRLS uses a data base management system known by the acronym RAPID (Relational Access Processor of Integrated Data Bases). GIRLS and RAPID run on IBM 370 compatible hardware with GIRLS requiring approximately 2 million bytes of storage. At Statistics Canada, we have an Amdahl 470/V6 and IBM 3330 disk drives. There are backup, restore, and recovery procedures built into the system.

Release 2 of the system was developed over the past year. This version has enhanced the

retrieval reporting capabilities of the system. In addition, the system has been installed at other institutions. An educational kit is being developed to assist new users of the system, and additional systems documentation is being prepared.

The system has been used for a wide variety of research applications [5]. Some of the research products will now be described.

4. THE PRODUCTS

The agencies that have sponsored and currently are sponsoring linkage studies represent a mix which includes not only provincial and federal interests, but also a strong representation of a non-governmental sort (see Table 1). Requests are coming from regulatory agencies such as the Atomic Energy Control Board (AECB), federal agencies such as Health and Welfare Canada and the Canadian Armed Forces, industry, provincial agencies, and universities both within Canada and the United States.

Starting point records for the various epidemiological follow-ups carried out so far comprise a wide assortment of administrative and other kinds of microdata files. These include ad hoc local files (e.g., nominal rolls created using the personnel, pay and pension records of the various employers), specialized centralized registers (e.g., a professional register of certified funeral directors and embalmers, and a provincial Workmen's Compensation Board (WCB) file of certified miners), records of employment (e.g., a large Unemployment Insurance Commission sample of the Canadian labour force), special survey records (e.g., the Nutrition Canada survey), vital registrations (e.g., British Columbia birth registrations), and special provincial and federal disease registers (e.g., Alberta cancer registry and a federal tuberculosis registry).

The studies to date are concerned with the long-term consequences of various occupational environments, medical treatments, diagnostic procedures, reproductive patterns, lifestyles and other environmental factors. In addition, some of the studies have had to do with organizing cancer incidence and survival data.

The Ontario Miners Study.--In Ontario, the Royal Commission on the Health and Safety of Workers in Mines [6] utilized two magnetic tape files to assess the risk of death among uranium miners. The first was the Ontario Nominal Roll maintained by the Ontario Workmen's Compensation Board. This contained employment histories for about 16,000 uranium miners for the period 1955-1974. The second was the Mortality Data Base at Statistics Canada.

This study identified about 950 miners who had died, and indicated that among these there was an excess of lung cancer. Among the uranium miners who died, there was almost twice the expected rate of lung cancer (81 deaths instead of 45).

In 1976, the first guidelines were developed and approved for the medical evaluation and claims adjudication of lung cancer cases brought before the Ontario Workmen's Compensation Board relating to exposure in uranium mining operations. These guidelines were based mainly upon Colorado observations and Czechoslovakia data. In 1979, based on new evidence from the

Table 1.--Agencies Involved in Long-Term Medical Follow-up Using Record Linkage.

Kind of Agency and Nature of the Study	Number of Individuals
A. U.S.A. research institution	
1. Ontario morticians (formaldehyde)	1,500
2. Bendix employees	1,700
B. Canadian universities	
3. Breast cancer and age at first birth	300,000
4. St. Regis fluoride study	2,500
C. Labour - management - university	
*5. INCO nickel workers 1940-1976	62,000
6. Falconbridge nickel workers	12,000
7. INCO-Falconbridge - Uranium internal linkage	93,000
D. National Cancer Inst. of Canada	
8. Isoniazid and cancer in tuberculosis patients	64,000
9. Fluoroscopy and cancer in tuberculosis patients	100,000
10. Canadian Labour Force - 10% sample	700,000
11. Railway workers	18,000
E. Provincial Royal Commission	
12. Ontario Uranium miners	16,000
F. Provincial labour depts. & WCB	
13. Ontario miners nominal roll	57,000
G. Crown corporations	
14. Eldorado uranium workers	21,300
15. Atomic energy workers (AECL)	20,000
16. Eldorado Nuclear Limited - Ontario miners internal linkage	73,000
H. Provincial cancer registries	
17. Alberta cancer registry death clearance	175,000
18. Ontario cancer registry reporting system	125,000
I. Federal depts. (including AECB)	
19. Infant death - birth linkage (1971 births)	6,000
20. Newfoundland fluorspar miners	2,000
21. Nutrition Canada Survey participants	20,000
22. Infant birth - death linkage (1978-1980 births)	10,000

*INCO refers to the International Nickel Company.

Royal Commission study and others, new and the currently operational guidelines were developed for Ontario [7].

The Ontario Workmen's Compensation Board and the Ministry of Labour are currently working on an in-depth extension of this study [8]. The study population now consists of 17,000 uranium miners, 33,400 non-uranium miners, 750 salt miners, and various other industrial groups.

The extension as planned is a multi-disciplinary project involving researchers from a number of different institutions. The major activities at Statistics Canada have consisted of establishing the mortality experience of the cohort, and evaluating the efficiency of the computerized matching procedures, especially with respect to workers who may have moved from one industry or company to another. This later step will require that there be an additional linkage with an Eldorado Nuclear uranium miners file. We are in the midst of these two aspects of the project. The death match has been completed, and analysis of the results is in progress.

With the collaboration of the various agencies, the study in its entirety will examine a number of factors which might well affect the dose-response relationships. These include:

- (a) influences in the mine environment - other than radon daughters - that might alter the likelihood of lung cancer mortality;
- (b) the effect of prior or subsequent non-uranium mining on lung cancer risk from uranium mining;
- (c) the effect of age, as well as age at time of exposure, on lung cancer risks;
- (d) questions of latency and the possible dependence of latency on age at time of exposure;
- (e) smoking as an important factor in lung cancer risk;
- (f) histological type of cancer in relation to the various parameters of exposure and age.

INCO and Falconbridge Nickel Workers.--In 1976, the management and union of INCO commissioned researchers from McMaster University to conduct a mortality study. The initiative for the study came from a joint union-management committee on occupational health set up by INCO Metals Limited and the United Steelworkers of America as a result of 1975 negotiations over renewal of their three-year agreement. Although several epidemiologic studies of mortality patterns in nickel workers had been reported, there had been no comprehensive study of the INCO work force in Canada. The publication of the National Institute for Occupational Safety and Health (NIOSH) nickel 'criteria' document early in 1977 [9] and the intention to introduce a new nickel standard in the United States, pointed to the need to study all parts of the nickel production operation as pertaining to health.

The study's primary objectives are therefore to compare both (a) the rates of mortality from various causes in nickel workers versus those of the general public, and (b) these mortality rates between various parts of the copper/nickel refining process from mining through to finished metal.

McMaster University and INCO assembled a nominal roll which involved the identification of over 54,000 INCO employees in the Sudbury region, and these were followed up over a 27-year period. A report has now been prepared describing the findings relating to the mortality patterns over the 1950-76 period, among the workforce as a whole and in major sub-groups [10].

Four types of cancer - nasal, larynx, lung, and kidney - were singled out for special attention because of pre-existing suspicion of being related to nickel exposure. In addition,

data on other sites were tabulated to obtain further evidence of possible excess cancer risk.

In the recent report by McMaster, in the analysis of the four a priori causes of death, they strongly verified the risk of lung and nasal cancer among workers in the sinter plants, but, with the exception of kidney cancer, could find very little evidence of excess risks to those employed in other parts of the plant. A consistent, but modest, risk of kidney cancer has been noted but does not seem to be associated with any particular area or activity.

The mortality search is now being extended backward using 1940-49 death records. A study of Falconbridge nickel workers is also being conducted. An additional linkage is in progress which will help identify individuals who moved from one plant to the other. This will enable more complete work histories to be accumulated.

Eldorado Nuclear Limited Workers.--There has been extensive work at Eldorado Nuclear Limited in compiling a nominal roll of 21,000 workers employed by them as far back as 1932 [11]. A special effort was made to determine how accurate an automated search of the death record file was, and the circumstances under which it would be more reliable. To do this, comparisons were made with outcomes from corresponding manual searches. For both kinds of search, the accuracy is highly dependent on the specificity of the identifying information common to the work record which initiates the search and to the death record.

Radiation Workers.--There have been a great number of requests for assistance, from those interested in studying the effects of radiation on human populations. For example, in the 1950's approximately 850 Canadian Armed Forces personnel witnessed nuclear tests in Australia and Nevada, and participated in the 1953 and 1958 nuclear reactor 'clean-up' operations at Chalk River. The mortality experience of the Canadian military services group is currently being determined. Military service personnel will eventually also be included in the Atomic Energy of Canada Health Study [12].

Asbestos Workers.--Public hearings are currently being held by the Royal Commission on Matters of Health and Safety Arising from Use of Asbestos in Ontario. A study is in progress for the SRI International in California, and the Ontario Ministry of Labour, regarding former workers at Bendix at Windsor, Ontario. The plant was involved with the use of asbestos in the manufacture of brake linings.

Monitoring of Occupational Groups.--In addition to studies of occupational groups already thought to be at high risk, there is a need for a systematic monitoring of substantial numbers of persons in the working environment to determine whether unsuspected risks might be identified. For this purpose it would be desirable to generate ongoing work histories for a continuing sample of the labour force, in which occupation and kind of industry are finely coded annually. Where questions are raised about the long-term consequences of work in a particular occupation, it is the long-term work history that is most relevant, and mere knowledge of the occupation at one point in time is a poor substitute. The capacity to generate work histories did exist in the now discontinued 'Book Renewal Cards', which

were filled out annually by contributors to unemployment insurance. This older file represents about a 10% sample of the Canadian labour force. Their work histories over a six year period have already been successfully used by the Epidemiology Unit of the National Cancer Institute of Canada in a study of occupational cancer and mortality [13]. A present-day substitute for this discontinued work history file has yet to be devised.

Monitoring Reproductive Outcomes for Genetic Effects.--Much of what has been discussed to this point has had to do with cancer. Reproductive outcomes are also of interest. The possibility that human mutation rates may have been increased by exposures to ionizing radiation and to the complex chemicals which accompany industrialization has been raised repeatedly in recent years. Public concern has become a very tangible factor in developing governmental policies and regulations. There is therefore a clear need to develop methods for the identification of populations at possible genetic risks, and a further need to develop consistent and acceptable data bases aimed at determining whether the presumed risks have actually been realized. In particular, it is desirable that possible carcinogenic as well as genetic effects be considered together, since an increased germinal mutation rate today might be an advanced warning of an increase in malignancy rate 10-20 years hence.

An international symposium held in Ottawa in 1980 [14] provided a forum for reviewing the current status of research in monitoring human populations for genetic effects, and for discussion of the directions that future activities in this area might take. One of the problems in assessing human genetic risk from experimental data is that it is not known if there is any quantitative correspondence between the effects observed in laboratory animals and those that might occur in man. Therefore, it is evident that there is a need to monitor human populations to enable the detection of increased mutation frequency.

Breast Cancer Study.--Birth registrations may serve as starting point records in follow-up studies to detect delayed risks of various kinds, and not only to the child itself. For example, in one such study they have been used to determine the subsequent risk of death from breast cancer among the mothers, as influenced by the ages at which they had their first child [15]. The prior evidence which prompted the study, suggested that early reproduction might have a substantial protective effect. Additional data were needed, and could be obtained in quantity from the vital registration system by using birth records to search out the subsequent maternal death registration.

The Nutrition Canada Survey.--The Nutrition Canada Survey was planned in the late 1960's and was conducted in the period 1970 to 1972 by Health and Welfare Canada. Dietary and other information was obtained on some 19,500 Canadians, who formed a systematic sample so that the data could be stratified later according to geographic location, age, sex, income and population density. A wealth of information was collected, to do with various individual

characteristics, circumstances, and habits that are generally believed to substantially influence future health. This file is being matched against the Mortality Data Base.

Death Clearance of Cancer Registry Files.--

Upgrading of the national cancer files has as its aim the creation of a multi-purpose facility, capable of yielding systematic data on a wide range of questions pertaining to cancer. Such questions will have to do with the geographic distribution of the disease, trends over time, and differentials of incidence with respect to population sub-groups. They are likely also to deal with differences in survival times. Death clearance of the National Cancer Incidence Reporting System file is an obvious ultimate goal.

As an initial step, death clearance for the Alberta cancer registry is being carried out. The procedures and experience established for working with the Alberta records will set a pattern for the future. Comparison of active versus passive follow-up, with respect to costs and accuracy, are also of interest.

Organization of Provincial Cancer Incidence Files.--Currently there is collaboration between the Ontario Cancer Treatment and Research Foundation, the Epidemiology Unit of the National Cancer Institute of Canada, and Statistics Canada for purposes of creating an Ontario Cancer Incidence file. Use is made of existing data files where mention is made of cancer. Each year the Foundation receives 65,000 hospital separation forms, 15,000 death abstracts and 25,000 pathology new patient registrations from the Princess Margaret Hospital and the Foundation's regional treatment centres. Currently these reports are being linked to produce new Ontario Cancer Incidence data.

The GIRLS system was originally used at Statistics Canada for this project, and earlier this year the system was installed in Toronto so that the work could be continued there. The linkage uses both the two-file capability of the linkage system (e.g., for matching hospital separations to pathology reports) plus the internal-linkage option whereby a variety of record sources relating to the same individual are grouped together so that a composite record can be created.

Other provincial cancer registries have made inquiries regarding the use of the GIRLS system. The experience of Ontario in using existing data files for the creation and upgrading of cancer incidence data is of general interest.

Assistance in upgrading of provincial cancer registries can be viewed as part of an evolving capability to produce better national health statistics and epidemiological data.

5. CHOICE OF FUTURE DIRECTIONS

There are three main directions for future endeavours: (1) the development of new and much needed 'starting point' data bases which would identify, in a more systematic fashion than heretofore, the occupational and environmental circumstances of people, and which could be used to initiate the searches for subsequent health studies; (2) the evaluation, improvement and expansion of existing search and linkage facilities which identify health endpoints; and (3) the development of internal research projects

using national data resources available only within Statistics Canada (e.g., census and census of agriculture data files).

6. THE FUTURE--IMPROVING THE STARTING POINT DATA SOURCES

If there is to be a systematic national approach to the gathering of occupational and environmental health statistics, attention will need to be given to developing the starting point files which identify the current occupation and characteristics of the people. Several large existing files constitute a challenge for the future. Relevant particulars are contained in the census, the taxation records, and those of Employment and Immigration Canada. For example, a study of Canadian farmers using Canadian census of agriculture and household census data for 1971 has been proposed.

Often the limiting factor is the cost of data entry from original forms when the required information has not been previously captured. While details of possible procedures for the exploitation of some of these files have been considered, practical experience is still limited. It is proposed that testing and design of detailed operational procedures, where they do not already exist, should be worked out.

In addition, methods need to be developed for a more detailed examination of selected high-risk geographic areas as noted on the mortality atlas. Further demographic and socio-economic data can be obtained from census records. A small study of this nature is in progress, and this can be used to document the experiment and provide guidance for any larger developments.

Although the absence of name rosters of past employees in industry makes it difficult to obtain early evidence of delayed health effects, there is much that can be done prospectively. An important consideration in the design is the inclusion of an abundance of personal identifying information to take care of problems arising from errors and discrepancies in reporting and recording of such things as names and birth dates. A list of suggested identifying items to be included in any starting and endpoint record is given in Table 2.

7. THE FUTURE--IMPROVING THE ENDPOINT DATA SOURCES

Endpoints that are of major epidemiologic interest include genetic and congenital defects, reproductive problems, cancer, together with morbidity and mortality from other causes. Of the present data sources being developed, the Mortality Data Base itself requires some further improvement. The National Cancer Incidence Reporting System file may be expected to be more useful as a result of provincial developments and help given to the cancer registries. Moreover, the rearrangement of existing birth and marriage records, to make them more readily searchable, would be useful for genetic studies.

Experience in using the Mortality Data Base has indicated that an extended machine-readable record format would be desirable for the future. For example, the occupation and industry information as reported on the source death registrations are not currently being coded. Further particulars recorded on the source document such as city or place of birth, complete parental given names, spouse's full name,

Table 2.--A List of Items to be Included on "Starting" and "Endpoint" Records

- | | |
|--------|---|
| * 1. | Surname |
| * 2. | Previous surname (if any) |
| * 3. | First given name |
| * 4. | Second and other given names |
| * 5. | Usual name (or nickname) |
| * 6. | Sex |
| * 7. | Birth date (year, month, day) |
| * 8. | Birth province or country |
| * 9. | Birth city or place |
| * 10. | Father's surname |
| * 11. | Father's first given name |
| * 12. | Father's second given name |
| # 13. | Father's birth province or country |
| 14. | Father's birth city or place |
| # 15. | Father's birth date (or age) |
| * 16. | Mother's maiden surname |
| # 17. | Mother's first given name |
| # 18. | Mother's second given name |
| # 19. | Mother's birth province or country |
| 20. | Mother's birth city or place |
| # 21. | Mother's birth date (or age) |
| * 22. | Marital status |
| * 23. | Spouse's birth surname |
| * 24. | Spouse's first given name |
| 25. | Spouse's second given name |
| 26. | Spouse's birth province or country |
| 27. | Spouse's birth city or place |
| 28. | Social Insurance Number |
| 29. | Health Insurance Number |
| * 30. | Place of residence - province or country |
| 31. | Place of residence - complete address including postal code |
| * 32. | Date of event |
| * 33a. | Last known alive date (e.g., date of last contact) |
| 33b. | Date hired by company |
| 33c. | Date left company |
| 34. | Principal lifetime occupation - type of work, type of business, length of time worked |
| 35. | Other items where applicable (e.g., birth order of child, status of birth, religion, race, etc.) |
| * 36. | Control code to indicate the kind of event |
| * 37. | A control code digit to indicate whether alternative entries for the same event are being recorded (e.g., where an individual may have alternate spellings for surname) |
| * 38. | A unique number |
| 39. | Where applicable, an indicator to denote whether the individual is known dead, the date of death, and the province or country of death |

NOTE:

- *,# Top priority should be given to collecting the items identified with asterisks. For genetic studies, additional parental variables will be required, particularly those denoted with '#'. Information relating to diagnostic procedures, work histories, exposure histories and such, plus updates are added to the basic record. For marriages, the record should identify the groom, bride, groom's parents and the bride's parents.

residence, and postal codes would be helpful for purposes of increasing the accuracy of death searches. Birth date information could be improved on the historical files by linkage with administrative files on which these are more accurately reported. Further, quality assessment of other items recorded on historical files is required, and steps need to be taken to facilitate use of historical coding schemes (e.g., disease and geographic codes).

Where fertility is of interest in indicating a health effect, the birth registrations may be considered as endpoint records. Marriage records can also be used as an intermediate step to get name changes at marriage for females. Use of existing marriage and birth records on a historical basis would involve considerable standardization and rearrangement of existing files.

8. THE LAW

Statistics Canada does carry responsibility for the confidentiality of the vital and health records which are entrusted to it. There are several pieces of legislation which define what we may or may not do. Most important are the Statistics Act, the recent federal Human Rights Act, Orders-in-Council pertaining to vital statistics, and the various provincial statistics acts or their equivalents.

9. CONCLUSION

To sum up, Statistics Canada in close collaboration with interested provincial and national agencies, has taken steps to develop the files and facilities required to do long-term medical follow-up studies on a national basis. This has been a multi-disciplinary, collaborative effort. These are very basic research tools.

We are rather excited about the potential these kinds of studies have in their humanitarian objectives (e.g., identifying diseases that may be preventable), their potential scientific output, and in development of new computer techniques for carrying out similar epidemiological studies. The aim is to improve the quality and extent of our statistical records, and here existing administrative data files are important. Epidemiologists should capitalize on recent computer developments, particularly the use of probabilistic matching techniques, new ways for organizing large data bases and the use of colour graphics in their research work. The approach described makes it possible to reduce the cost of many research studies, and will make possible a greater number of studies on a scale which could not have been seriously contemplated in the past.

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