AECL-7828

ATOMIC ENERGY OF CANADA LIMITED

L'ENERGIE ATOMIQUE DU CANADA, LIMITEE

A STUDY OF THE HEALTH OF THE EMPLOYEES OF ATOMIC ENERGY OF CANADA LIMITED

II. IMPLEMENTING THE STUDY

ETUDE DE LA SANTE DU PERSONNEL DE L'ENERGIE ATOMIQUE DU CANADA, LIMITEE

II. MISE EN APPLICATION DE L'ETUDE

J. L. Weeks, L. H. Johnston

Whiteshell Nuclear Research Establishment

Etablissement de recherches nucléaires de Whiteshell

Pinawa, Manitoba R0E 1L0

September 1984 septembre

ATOMIC ENERGY OF CANADA LIMITED

A STUDY OF THE HEALTH OF THE EMPLOYEES OF ATOMIC ENERGY OF CANADA LIMITED
II. IMPLEMENTING THE STUDY

by

J.L. Weeks and L.H. Johnston

Whiteshell Nuclear Research Establishment
Pinawa, Manitoba ROE 1LO
1984 September

AECL-7828

ÉTUDE DE LA SANTÉ DU PERSONNEL DE L'ÉNERGIE ATOMIQUE DU CANADA, LIMITÉE
II. MISE EN APPLICATION DE L'ÉTUDE

par

J.L. Weeks et L.H. Johnston

RÉSUMÉ

L'étude de la santé du personnel de l'Énergie Atomique du Canada, Limitée est un programme qui a été établi en 1980 dans le but de déterminer, à long terme, les causes de mort dans une population comprenant quelque 14 000 employés et ancien employés de l'EACL. Un rapport précédent (AECL-6813) a décrit les mesures prises pour effectuer cette étude. Le présent rapport décrit la manière dont on a mis cette étude en application et comprend une discussion de certains développements récents qui ont eu une influence sur les études épidémiologiques de la santé des travailleurs sous rayonnements.

L'Énergie Atomique du Canada, Limitée
Établissement de recherches nucléaires de Whiteshell
Pinawa, Manitoba ROE 1LO
1984 septembre

AECL-7828

A STUDY OF THE HEALTH OF THE EMPLOYEES OF ATOMIC ENERGY OF CANADA LIMITED
II. IMPLEMENTING THE STUDY

by

J.L. Weeks and L.H. Johnston

ABSTRACT

The Atomic Energy of Canada Limited Employee Health Study is a program that was established in 1980 to determine, over the long term, the causes of death in a population consisting of some 14 000 AECL employees and past employees. In a previous report (AECL-6813) the steps taken to set up the study were described. The present report is a description of the way in which the study was implemented, and includes discussion of some recent developments that have had a bearing on epidemiological studies of the health of radiation workers.

Atomic Energy of Canada Limited
Whiteshell Nuclear Research Establishment
Pinawa, Manitoba, Canada ROE 1LO
1984 September

AECL-7828

CONTENTS

1. INTRODUCTION

Since the publication of a previous report describing the steps taken to set up the Atomic Energy of Canada Limited (AECL) Employee Health Study [1], a number of reports of similar studies undertaken elsewhere in the world have appeared in the literature (see, for example, references 2-4). There has also been discussion of the value of epidemiological studies of the health of radiation workers and of the so-called Healthy Worker Effect (HWE) that is frequently observed in studies, whether of radiation workers or of other populations occupationally exposed to potentially hazardous substances or agents.

A great deal of effort and not a little money is being spent on studies of the health of radiation workers and it is proper to ask whether it is likely that useful information will be produced by them. The question has been put very clearly by Briscoe [5]. It is less clear that those who contend on this issue are necessarily talking or writing about similar end-points. If the purpose of an epidemiological study is to determine the precise relationship between exposure to ionizing radiation and the subsequent development of disease, then little encouragement can be given to a would-be investigator. There are several reasons for this position, among them the relatively small sizes of the populations being studied, the relatively low occupational exposure to radiation in these populations, and the comparatively low incidence of many of the diseases believed to be associated with radiation exposure. In a reply to Briscoe, the purpose of an epidemiological study was defined as follows [6]: "to determine the incidence of disease in a population and to relate this information to factors that may have a bearing on observed variations in disease patterns". It is a definition that fits very closely the objectives of the AECL Employee Health Study.

Relating to this topic, Reissland in a recent paper [7] wrote: "Despite the difficulties implied by estimates of the size of study necessary to achieve sufficient statistical power, those who incur the risk and those who speak on their behalf are entitled to an investigation of the efficacy of radiological protection by a follow-up study of all those occupationally exposed to ionizing radiation". Later in the same paper, Reissland referred to the importance of studies underway in Canada, the U.S.A. and the United Kingdom, suggesting that such studies will provide useful information about the upper limits of radiation risk, but he cautioned that, unless the values for risk proposed by the International Commission on Radiological Protection (ICRP) grossly underestimate the true risk, none of these studies will have sufficient power to provide new numerical estimates of low-dose radiation effects. Reissland went on to suggest that if it were possible in some way to combine the findings of these studies, the significance of the results might be improved and information on the induction rates for some less common malignancies might be forthcoming. The suggestion merits careful consideration, but it will be necessary to recognize that major differences in the incidences of specific neoplastic diseases in the various regions of the world may introduce a considerable difficulty that would have to be resolved before valid results could be achieved.

Fry and her colleagues [3] have described a study designed to determine the health experience of those U.S. Department of Energy (DOE) employees who, during the course of their occupation, had been exposed to ionizing radiation in excess of 50 mSv in any one year. (The "More Than 5 Rem Study"). The cohort for this study consists of some 3200 employees and ex-employees located at a number of sites in the United States. The total cumulative occupational exposure reported for the cohort is 680 person-Sieverts (PSv), or 68 000 person-rem. Acute accidental exposures of $\geq$ 250 mSv incurred by 49 individuals account for some 120 PSv of the total. The study is designed to take into account non-radiological hazards to which radiation workers may be exposed. Provision is also made for comparison of the health experience of workers with different exposure levels in the cohort.

The incidence of the leukaemias in irradiated people is a matter of major concern to those who study the health of radiation workers. Of interest in the context of this question is the report by Linos and her colleagues [8] who, in studying the incidence of leukaemia in residents of Olmstead county, Minnesota, were unable to demonstrate any statistically significant increase in the risk of developing leukaemia in patients who had received radiation doses of up to 300 rads*during the course of medical treatment. These amounts were administered in divided doses over long periods of time. The interest of this paper is of course tempered to some extent by reservations concerning sample size, dosimetry and the potential bias introduced by the fact that all the participants in the study needed medical treatment for one reason or another, and were not therefore "normal" subjects.

In his contribution to reference 4, Hamilton provided information on the results obtained up to 1982 in the Ontario Hydro study. A Standardised Mortality Ratio (SMR)**of 0.58 for cancer deaths among nuclear workers in this study has been commented upon as an example of the HWE; however, there are some reservations about the general applicability of the concept of a Healthy Worker Effect. The finding of such an SMR 10 years after the commencement of the study is well within the latency period for most cancers, and it will be necessary to obtain further information over many more years before a firm conclusion can be reached.

At this point it may be useful to consider the Healthy Worker Effect more closely. The effect has been considered at some length by Wang and Miettinen [9]. These authors have pointed out that in occupational mortality studies, it is usual to compare the mortality of workers in a particular occupation with that of the general population. The former is often found to be lower than the latter, and the difference is known as the Healthy Worker Effect. Wang and Miettinen suggest that if therapeutic research were conducted in an analogous manner, treated patients would be compared with the general population for any criterion of outcome. Experience would show that the treated group usually has a worse outcome than the reference population, and the difference might be described as the "sick

---

* 1 rad = 10 mGy

** The Standardised Mortality Ratio is defined as the ratio of deaths at all ages observed in a given population to the deaths that would have occurred in that population if in each age (and sex) group it had been exposed to some selected standard rates.

patient effect". It follows, therefore, that the object of an occupational mortality study should not be to determine the health effects of, for example, chemical manufacturing, copper smelting or coke production, but should and can be to define the effects of occupational exposure to benzene, arsenic or coal tar volatiles. The observation is important since it confirms the long-term need in the AECL study to compare the health of radiation workers with that of others in the cohort who, although they have not been occupationally exposed to ionizing radiation, are in other respects similar to the exposed population.

Baverstock [10] makes a rather similar point that an SMR of significantly less than 1.00 is often called the Healthy Worker Effect, but an HWE is not in fact observed as such, it is merely offered as an explanation for a reduced SMR. Such a reduction may be due to an HWE, but other explanations should not be excluded. Baverstock supports Reissland's statement [7] concerning the value of epidemiological studies for establishing an upper level of risk in an occupation, and reaffirms the need for better understanding of the mechanisms by which ionizing radiation induces cancer in man. With this understanding, the epidemiology of occupationally exposed populations may be more confidently interpreted.

The many discussions of the epidemiology of radiation workers that have taken place during recent years have served both to refine the AECL Employee Health Study and to confirm its original purpose. Some changes have been made in the methods of the study, but the initial purpose remains to determine the causes of death of those who have been employed by AECL. Recognizing that many members of this population have been radiation workers, as defined by the Regulations made under the Atomic Energy Control Act, the association between occupational exposure to radiation and eventual cause of death will be investigated to the extent permitted by the information that results from the study.

2. THE AECL EMPLOYEE HEALTH STUDY

Here it may be helpful to describe briefly the AECL Employee Health Study, a full account of which appears elsewhere [1].

The Canadian nuclear research program commenced in 1944 and led to the formation in 1952 of Atomic Energy of Canada Limited. This Crown Corporation is responsible for research and development programs in support of the CANDU nuclear reactor and related nuclear technologies. More recently, responsibility has been assumed for the Canadian Nuclear Fuel Waste Management Program. When the Health Study began, AECL had some 7000 employees located at several sites across Canada. The majority of the 4200 radiation workers are employed at the Chalk River Nuclear Laboratories (CRNL) in Ontario and the Whiteshell Nuclear Research Establishment (WNRE) in Manitoba. In this population, the accumulated occupational exposure of the whole body to ionizing radiation from external sources is about 200 PSv (as of 1984 January) with a current annual increment of approximately 10 PSv.

Discussion of, and planning for, the Health Study began in 1976 and the program formally commenced in 1980 April. Studies such as this are greatly helped by the availability of the National Mortality Data Base maintained by Statistics Canada. This contains information on the causes of death of Canadians dying in Canada since 1950. Access to the Data Base is strictly guarded by the Statistics Act and data are released from it in statistical form only. The Mortality Data Base and the more recently established National Cancer Incidence Reporting System (NCIRS) are major assets for the epidemiologist, and the AECL study has been designed for close linkage with them, making maximum use of records and computer systems already available within AECL.

The study population has been divided into three groups:

(1) Past employees at CRNL and WNRE (i.e. prior to 1980 January 1): 7021 names.

(2) Current employees at all sites (1980 July): ~ 7500 names.

(3) Employees joining any AECL site after 1981 January 1. These names constitute a separate registry and are not at present included in the study.

The program is being carried out in four phases:

(1) The identification of past and current employees (as defined in (1) and (2) above) by means of an Employee Identity Summary (E.I.S.) form (see Appendix A). The E.I.S. form is the basic tool of the study and has been designed to permit accurate linkage with the Mortality Data Base.

(2) The transfer of data from the E.I.S. forms to magnetic tape, together with accumulated radiation exposure data for past employees.

(3) Linkage of this tape with the Mortality Data Base to determine the cause of death for those who have died.

(4) The analysis of mortality data emerging from the first and subsequent linkages with the Mortality Data Base.

It is expected that the linkages will take place every three years until an adequate amount of mortality data has been accumulated. The analyses of data derived from the linkages will be undertaken by staff of the Epidemiology Unit of the National Cancer Institute of Canada (NCIC). By 1984 Phases (1) and (2) have been completed and the first linkage of the study tape with the Mortality Data Base (Phase (3)) has been made by staff of Statistics Canada.

Since the publication of reference 1, there have been no major changes in the concept of the Health Study. The changes made have been procedural, and include the preparation of a single master tape for the study, rather than separate tapes for the past and current employees, as described in Section 5.3.2 of reference 1. The Medical and Lifestyle Questionnaire (MLSQ) is in all major respects similar to that shown in

Appendix J of reference 1. The method for distributing the questionnaire differed from that outlined in Section 5.6 of the above reference and is described in Section 5 of this report.

3. LEGAL ASPECTS

In Canada, human rights, privacy, and the confidentiality of personal information are protected by legislation that can sometimes complicate, if not restrict, epidemiological studies. During the time in which the AECL Health Study was being designed, a considerable amount of thought was given to the implications of existing legislation. The most important question appeared to be that of consent by participants in the study. It was concluded that it would be unnecessary to obtain consent from "past" employees who would be included in the study. The reason for this conclusion was that no action, administrative or otherwise, arising from the study would be likely to have an effect upon a past employee. For "current" employees and for those who might in the future join the Company, the situation is different in that their conditions of work and service could conceivably be affected by decisions made as a result of a study in which they would take part. The possibility is remote, but cannot be excluded.

AECL is not listed in the schedule of departments, corporations and other bodies expressly made subject to the provisions of Part IV of the Canadian Human Rights Act, which is the relevant legislation. It was, however, recognized that the Health Study would be a long one, lasting over many years and there existed a possibility that the legislation could be amended during the lifetime of the study. This could have the effect of making mandatory, individual consent to future participation, such as the completion of questionnaires. It was decided that, as a matter of prudence in respect to the future activities of the study and of courtesy to employees, the study would be conducted in accordance with the spirit of the law, even though at the time this did not appear to be a legal necessity. All "current" and newly joined employees have therefore been asked to complete and return a form on which is indicated their consent or refusal to take part in the study. It was anticipated that some people would be reluctant to complete any form, and therefore an individual who does not wish to participate is required to make that refusal clear in writing. The Protection of Personal Information Regulations provide that a reply to the request for information shall be given by an individual within 30 days of its receipt. After 30 days, if no indication of refusal has been received, an individual may be deemed to have been consulted and to have consented to the use of the information for the purpose specified. For our study, it was decided that a 45-day "grace" period would be allowed; if no response had been received from an individual by the end of this period an E.I.S. form would be prepared from information available in the Personnel Records and included in the study.

In retrospect, both the courtesy and the prudence can be defended. In practice there has been an impact on the study, since 7.8% (588 out of 7555) of the current employee group have refused to take part in the study, and of the new employee group, a similar number have not consented.

The loss of this number of people reduces the statistical power of a study, a power that was not conspicuously strong in the first place, and it has been necessary to assess this situation, as discussed in Section 7.

Whenever a question is asked, the questioner implies a willingness to accept a negative response. In the present case, it is reasonable to propose that the decision should have been to observe the letter of the law rather than to attempt to observe its spirit. Had such an approach been taken, the limited power of the study would have been safeguarded in this particular respect. The decision is not one that can be unmade, but the situation is one that merits very careful consideration by organizers of future epidemiologial studies.

Legislative changes, such as those anticipated above, have in fact been enacted during the early part of the lifetime of the study. The Privacy Act, which became law on 1983 July 1 is based on the principles outlined in the Canadian Human Rights Act. It expands on that base by allowing an individual access to a greater amount of information than was previously the case, by making specific reference to the uses to which an individual's personal information can be put and by providing for the manner and extent to which government institutions can collect, retain and dispose of personal information. While these changes make mandatory some of the approaches adopted voluntarily in setting up the study, they do not entail any major procedural changes.

4. ASSEMBLY AND HANDLING OF DATA

The AECL Employee Health Study commenced formally in 1980 April. The first task was to establish a study population with enough personal identifying information for an accurate linkage with the Mortality Data Base. The Employee Identity Summary form was used for this purpose. E.I.S. forms were distributed by personnel departments at each site in 1980 June to all full-time current employees (approximately 7500; see Table I). The forms already included basic information about the employee, such as name, birth date, marital status, SIN number, etc., as provided by the Central Personnel Record System (CPRS) data base.

TABLE I
CURRENT EMPLOYEES

Site	Consent	Refusal	No Response
Research Co. Head Office[1]	38	-	2
WNRE[1]	502	71	360
CRNL[1]	1620	110	611
Radiochemical Company	353	131	403
Engineering Company[2]	1645	123	587
Chemical Company Head Office[2]	68	10	8
Glace Bay Heavy Water Plant[2]	151	39	207
Port Hawkesbury Heavy Water Plant[2]	135	55	142
International[2]	9	1	5
Corporate Head Office	97	48	24
TOTALS	4618	588	2349 = 7555

[1] These units now comprise the Research Company of AECL

[2] These units now comprise AECL - CANDU Operations.

When undertaking such a large mailing, some difficulties are inevitable. Employees of AECL were advised of the study and its purpose by personal visits to each site by members of the Health Study Steering Committee, by a company-wide General Notice to all employees, and by inserts in each site's bulletin or newsletter. Despite this extensive effort to inform employees of the value and purpose of the study, many employees disregarded the message. When faced with completing a rather extensive personal identity form, they could not understand the need for having to know, for example, mother's maiden name, for the purposes of a "health" study. Many persons declined to participate for this reason. At one site, forms were distributed in envelopes lacking a "confidential" annotation, which led prospective participants to believe that information they contributed would not be kept confidential. Others were apprehensive regarding the use of computers in the study, and believed computers could not guarantee confidentiality. One site was in the midst of a strike that delayed distribution of the form. When the strike was settled, it was discovered that the forms needed reprinting, which further delayed distribution, and when they were eventually mailed, consent forms were not included. Despite the difficulties encountered, of the more than 7500 employees eligible to take part in the study, 4618 (61.12%) consented to do so, 588 (7.78%) did not consent, and 2349 (31.10%) of those to whom E.I.S. forms had been sent did not respond in any way. As mentioned in Section 3, the legal position

with regard to the last group is that the data requested of them could, after a 30-day grace period, be extracted from the personnel files and included in the study. While this would provide a less complete identification profile than would have been obtained by personal completion of the form, it would provide reasonable certainty of a good match when the time came for linkage with the Mortality Data Base. Consequently, it was possible to include in the nominal roll for current employees approximately 92% of those who were eligible to take part in the study.

It was initially intended that data entry from the completed E.I.S. forms would be undertaken at each AECL site. However, subsequent discussions showed that the staff of the Data Entry Section at WNRE could transfer data from all sites to magnetic tape at WNRE. This would provide a consistent approach to quality control of the data and uniformity of data entry. Personnel staff at each site were therefore asked to send all completed E.I.S. forms to the study co-ordinator at WNRE. When received, the forms were sorted by site and stored alphabetically by name after initial scanning and the correction of obvious anomalies.

The next task for those working on the study was the follow-up of non-responders. In the administrative instructions (Appendix L of reference 1), sites were asked to institute a follow-up system to ensure completion of forms for all employees who had not declined to participate in the study. It soon became apparent that some sites had done this and others had not. The best method of determining non- responders seemed to be: (1) obtain a computer list of all employees by site, using the CPRS data base, (2) scan the computer list to eliminate persons who would not be included in the study (part-time employees, attached staff, etc.), and (3) compare the forms with the list. If a form had been received (either consent or non-consent) a check mark was placed beside the name. At the end of this exercise all names without a check mark were classified as non-responders. Once the non-responders were identified, E.I.S. forms were completed by using the CPRS data base which was able to supply enough information for a satisfactory linkage with the Mortality Data Base at Statistics Canada.

In parallel with this lengthy task, work commenced on the preparation of E.I.S. forms for past employees. These were completed (as far as possible) by reference to personnel files. Although this task was limited to the files of past employees at CRNL and WNRE only, it did involve scanning some 7000 files and was very time-consuming. By the beginning of 1982, the assembly of E.I.S. forms providing the basic data for the study had been completed and radiation dose data, where available, had been added to the forms (see Appendix B).

In the case of past employees, the radiation dose entry represents the accumulated total exposure to ionizing radiation while in the employ of AECL, and in most instances it has been possible to include prior occupational exposure. This is not necessarily, however, a lifetime total, as exposure may have occurred after the period of employment with AECL. The National Dose Registry (NDR) maintained by the Radiation Protection Bureau of Health and Welfare Canada is the repository for records of occupational exposure to ionizing radiation in Canada. It is intended, eventually, to link the AECL tape with NDR, so that lifetime exposures may be more accurately determined.

At CRNL and WNRE, persons who had declined to participate in the study were sent individually addressed letters from the study coordinator, again describing the study and its purpose and emphasizing the inclusion of as many AECL employees as possible, with the intent of having these persons reconsider their decision to join the study. A number of employees did reconsider and were subsequently added to the study group.

It was decided that the entry of data on onto magnetic tape would commence with current employees, as the data gathering for past employees had not been completed. A block of numbers was allocated to each site, as described in Appendix C, but it was not expected that all numbers in the block would be used. This provided for the addition of any forms that might have been missed. Each form was stamped with an identifying five-digit Health Study Identification Number. Each was given this unique study number as a means of safeguarding and, if necessary, tracing it during the data entry process. This number would also be entered in the file as a numerical identifier for each entry. The consenting employees were stamped first,non-responders second, and those who had changed from non-consent to consent third; therefore, within each block of numbers allocated to a site there are subblocks. A record was kept of each number and to whom the number was allocated. A record was also kept of numbers that were missed when stamping, forms (with numbers) which were subsequently deleted, etc., in order to account for each number. Thus, what started as a bookkeeping system has already proven its value as an aid to the resolution of computer problems.

There were several areas on the form that required the use of a two-digit number code rather than a longer version, before entry on a computer. For example, the months of January, February and March were allocated codes of 01, 02 and 03, and were used when entering dates of hiring, birth dates and termination dates. Statistics Canada provided a list of two-digit numbers for place of birth. For example, Prince Edward Island was coded as 01, England as 21, and the United States as 41. The coding system is described in Appendix F of reference 1. After encoding was completed, the information was ready for transfer to magnetic tape in a form suitable for linkage with the Mortality Data Base. The details of this operation are described in Appendix D.

When the health study tape was sent to Statistics Canada, a field frequency and validity check (SAS run) was performed on the data. This check covered different categories or fields on the tape, and identified areas in which no data had been recorded, or in which data values were unexpected. Staff of the Data Entry Section at WNRE generated computer programs that were used to extract the areas of concern and to provide the corresponding health study identification numbers. Once the number was available, a manual recheck of the E.I.S. form could be done. The recheck would either confirm that the data were unavailable or would give basic information (such as name of individual) so that follow-up work could begin. The questions created by the SAS run fell into four categories:

(1) missing data (such as marital status; sex codes; first, second or third given names; birthplace codes; and last year known alive);
(2) data with unusual or unexpected values (such as birth year of 1971, or birth day of 57);
(3) data entered onto tape in a manner inconsistent with the Statistics Canada format; and
(4) data that required clarification or explanation.

In many cases the information was either unavailable, or an attempt to obtain it needed very extensive effort. In the latter case, the value of, or requirement for, the information had to be weighed against the amount of effort required to obtain it. For example, the amount of effort required to trace approximately 6000 fathers' birth places far outweighed the value of the information that might be obtained. In the case of missing or unusual birth days, months or years (approximately 75 occurrences), or missing sex codes (approximately 11 occurrences), this information was considered important for a good linkage with the Mortality Data Base, and an extensive effort was made to obtain it. In the case of missing entries for last year known alive, it was determined that the majority of occurrences were from the "current employees" section of the tape (group 2, Section 2). Since this group had completed their E.I.S. forms in 1980, it was apparent that they were alive in 1980 and it was a simple operation to insert that year into the file. Many of the missing first names were identified by cross-referencing Box 3 on the E.I.S. form (first given name) and Box 6 (usual name or nickname). The third given names were missing due to a computer difficulty. The names (when present on the E.I.S. form) had been entered on the computer, but did not appear on the final tape. It was decided that the first, second and usual names would provide sufficient information for a good linkage. A similar problem occurred with dates of death when it was discovered that the final digit in the date of death had been dropped. After obtaining the health study identification numbers for these occurrences, the dates were obtained by referring to the E.I.S. form and were re-entered onto the tape. An extensive effort was made to obtain any dates of death that were incomplete. Unusual values were discovered in the "Other Surname" field. These values were the result of using that field as a cross-reference area, i.e. if any duplicate entries were discovered (two entries for one individual), this field was used to refer one health study identification number to another. It was decided to place all information under one entry and cancel the duplicate entry, thus eliminating the invalid characters in the "Other Surname" field. Some inconsistencies with the Statistics Canada format were encountered in the method of entering data into the computer. These were rectified as, for example, by changing a surname of ST. PIERRE to STPIERRE, thus eliminating both the period and the blank space.

The "clean-up" of the health study tape was greatly aided by the use of computer technology. Several programs created by the staff of the WNRE Data Entry Section, to extract areas of concern from the tape, provided health study identification numbers and other basic information, allowing quick follow-up and clarification of these areas. To attempt this task by manual search through approximately 14 000 records would have been a very time-consuming task.

5. MEDICAL AND LIFESTYLE QUESTIONNAIRE (MLSQ)

After distribution of the E.I.S. forms, further consideration was given to the MLSQ. This questionnaire is described in Section 5.6 and Appendix J of reference 1. There continued to be reservations concerning the quality of the data that could be obtained by using the MLSQ. It was, however, decided that an effort should be made to cover as many as possible

of the confounding factors inherent in the Health Study, and it appears that a similar approach is being considered by those responsible for other studies of radiation workers [2,3].

The MLSQ as eventually used is shown in Appendix E. It differs in no major respect from the questionnaire described in reference 1. There was extensive discussion of the ways in which the questionnaire could be administered, and the available options were eventually narrowed to three:

(1) Distribution of the MLSQ to all current employees of AECL for completion and return to the study coordinator.
(2) Completion of the MLSQ by plant physicians for all current employees during visits to Plant Clinics.
(3) Distribution of the MLSQ by AECL on behalf of the consultants (Epidemiology Unit, NCIC) to whom the completed questionnaires would be returned.

It was concluded that, even though the MLSQ was designed to preserve the anonymity of respondents, option (1) could entail an apparent breach of confidentiality that could perhaps reduce the number of employees responding. That option was therefore discarded. The second option has obvious attractions and would have added greatly to the amount of data available in employee medical files. Unfortunately, the lack of a formal company medical organization made the implementation of this option impractical. (It may be noted here that there is a continuing need to improve the quality and retrievability of data contained in employee medical records.)

It was decided that the third option would be used, as it would most clearly preserve the confidentiality of sensitive medical information. A covering letter from the consultants (Appendix F) was prepared for distribution with the questionnaire. This letter was addressed by using the Central Personnel Record System (CPRS), and matched to an MLSQ bearing only the unique personal study number, as a means of linkage to the E.I.S. data contained in the study data base. These two items were then packed together with a franked-addressed envelope for the return of the questionnaires to the consultants at NCIC. French language versions of the MLSQ and covering letter were prepared for employees who preferred to use that language. Some 7500 individual packages were sent in bulk to sites for distribution.

In this large task, considerable use was made of computer technology, and the whole MLSQ operation, from finalization of design to distribution, was completed during 1982/83 in the relatively short time of three months. Soon after distribution commenced, a problem was encountered. The program required that letters and envelopes be addressed using surname and given names (Boxes 1, 3, 4, 5 on the E.I.S. form, Appendix A). It quickly became apparent that in completing the E.I.S. form, a number of employees had not used boxes 3, 4 or 5 but had instead filled in box 6, "usual name or nickname". The computer program did not require scanning of this box and a large number of MLSQ packages arrived at sites bearing only the surname of the addressee and the unique study number. This was not a serious problem when there was only one person with that surname at a site, but with names such as SMITH or DUBOIS occurring very frequently, the potential for confusion was great.

It was at this point that the unique study number allocated to each participant proved its worth for the first time. The numbering system had been introduced as a precaution to keep track of the E.I.S. forms during data entry. The availability of the system enabled one of us (L.H.J.) to resolve the problem manually, and to ensure that the MLSQ packages were eventually received by the right persons. The task consumed much time, both at the study centre and on the part of the administrative staff at sites. It was finally completed after about six weeks, and something had been learned of the vagaries of computer technology. The incident had an aspect of light relief in that it enabled some employees to express in strong terms their mistrust of, and general superiority to, computerized systems, thus providing a measure of release for the frustration that many people feel when confronted with computers.

During the early months of 1983 completed questionnaires began to return to NCIC, and by 1983 August, 3305 English and 58 French questionnaires had been returned. The response rate thus far is 45% and it remains to be seen whether the quality and quantity of the information received will contribute usefully to the Health Study.

The MLSQ exercise has demonstrated quite forcibly the strengths and weaknesses of computer technology as applied to epidemiological studies. At this stage, no assessment can be made of the design of the questionnaire, but no questions have been asked about it and presumably no difficulties have been encountered. The information that can be retrieved, however, is largely subjective and unconfirmable as to lifestyle and anecdotal as to medical and occupational history. These concerns are common to all such questionnaires, and suggest that this type of retrospective survey is unlikely to be an adequate substitute for the organized recording of medical and occupational histories. It is theoretically possible to construct a fairly accurate medical history for any individual, provided that consent is given by that individual. In most organizations, however, the means for constructing an accurate occupational exposure history do not exist. In a study such as this, in which a major long-term objective is to attempt an assessment of the effects (if any) on health of occupational exposure to ionizing radiation, it is essential to identify exposure to other potentially harmful agents or substances used in industry. The means for making such identification reliable do not at present exist on an adequate scale.

6. RELATED STUDIES AT CHALK RIVER NUCLEAR LABORATORIES

In parallel with the main health study, population subgroups have been studied at CRNL. The first of these studies, by Myers and his colleagues [11], involved a group of 300 male employees who died, either during the course of their employment, or who were known to have died during retirement. The Standardised Mortality Ratios (SMRs) in this group for deaths from cancer, cardiovascular disease, accidents, and all other causes were 0.85, 0.94, 0.63 and 0.70, respectively. A second study, by Werner and her colleagues [12], was a follow-up of employees who were involved in "clean-up" work after the NRX reactor accident at Chalk River

in 1952. This population consisted of some 800 persons and was divided into two subgroups: (A) those who left the employ of AECL at some time after the accident and (B) those employees who continued to work with AECL. Because it is improbable that all the deaths occurring in Group A have been identified, SMRs for this group have not been calculated. In Group B, SMRs for cancer, cardiovascular diseases, accidents, and all other causes were 0.83, 1.03, 0.69 and 0.70, respectively. Werner and her colleagues have also undertaken a similar follow-up of 537 employees who worked on the decontamination of the NRU reactor after an accident in 1958 [13]. In this group, SMRs for the categories given above were: 1.07, 1.09, 0.80 and 1.01, respectively. For the NRX and NRU groups combined (905 employees), SMRs were 0.94, 1.01, 0.81 and 0.86, respectively, whereas for a smaller group (194 employees), whose members worked on clean-up during both accidents, SMRs were 0.79, 1.28, 0.42 and 0.61, respectively.

It must be emphasized that these observations relate to specific population subgroups at particular points in time. They are not a final analysis of the total mortality experience of these subgroups.

7. DISCUSSION

In recent years, issues have arisen that have a bearing on the Health Study, and indicate directions for future work related to the study. Enterline and Marsh [14] have drawn attention to the need for cohort verification in epidemiological studies related to occupational exposures. The missing record can introduce a bias into the calculation of an SMR and where the extent of this bias is unknown, the effect can be serious. The possibility exists that in a multi-site study, the errors attributable to bias may to some extent be compensatory, but the degree to which such compensation will apply to the Health Study cannot at present be determined. It is known that a number of current employees have refused to take part in the study. This introduces a bias and it is important to ensure that such a bias is not compounded by others, such as, for example, that some available employee records may have been missed in preparing the data base for the study.

The accuracy of death certificates is also a question that exercises those who are involved with epidemiological studies. Gau and Diehl [15] have shown that in the United Kingdom, when more than one organ system is involved, fewer than half of the certifying physicians were agreed on the cause of death. Similar comments have been made by Alderson and colleagues [16]. However, experience thus far with the AECL Study has indicated that there is a high degree of accuracy in the certification of deaths. In one series of 150 deaths occurring during employment since 1966, there was only one case in which the information on the death certificate was probably incorrect.

In Section 5 of this report, reference was made to the need to develop accurate worker-exposure histories. Such histories relate to exposures other than ionizing radiation, and are more complex than the radiation exposure records required by regulations governing the nuclear industry. Progress is being made in the development of worker-exposure

histories by some of the larger industrial organizations, and it is already possible to foresee that the maintenance of this type of record will become mandatory in many jurisdictions and will, in time, provide data from which non-radiation exposures can be assessed in conjunction with information obtained from radiation-dose registries. It is recognized that ionizing radiation may interact with other potential carcinogens in the genesis of disease. Consequently, the availability of exposure histories related to factors other than ionizing radiation may well be of help in assessing the attributability of occupational disease.

In an interesting discussion of attributability, Enterline [17] has pointed out that in the case of lung cancer occurring in an asbestos worker, it cannot be stated with certainty that a cause-effect relationship is present, since to make such a statement would imply that the asbestos exposure somehow blocked the possible effect of all other cancer-causing agents in the environment. Enterline goes on to show, however, that if good epidemiological data are available, a simple calculation will give an indication of the probability of a causal relationship, as follows: where the relative risk (RR) exceeds 1

$$\text{Percent Probability (PP)} = \left(\frac{RR-1}{RR}\right) 100$$

The calculation of the probability that a given lung cancer is attributable to asbestos exposure will thus depend on the availability of related data, such as the number of years since first exposure and the intensity of exposure. Given these data, RR can be calculated for exposure subsets and PP can be derived. Enterline emphasizes the need to take into consideration other factors such as smoking history, but suggests that smoking history, per se, does not significantly affect relative risks for smoking and non-smoking asbestos workers taken as separate groups. This observation is related to the apparent ability of asbestos to multiply the effects of other carcinogens. The possibility that ionizing radiation may have similar properties cannot at present be excluded.

Insofar as radiation is concerned, somewhat different approaches have been taken. The determination of "causative odds", described by Bond [18], has been discussed at length, and attention has been drawn to the potential shortcomings of this method for the calculation of attributability. A complex method, involving considerations such as ICRP risk factors, dose, length of employment, type of cancer and latent period, is being developed by the staff of British Nuclear Fuels Limited (BNFL). No information has yet been published about this approach, which is designed as a method for the asessment of compensability, but accounts of experience with it will be awaited with interest.

Whether the attributability of disease associated with occupational exposure is calculated on the basis of a relatively simple formula such as that described by Enterline, or whether a more complex approach is adopted, there will exist the need for good epidemiological data on the incidence of disease among radiation workers. The purpose of the AECL Employee Health Study, and of similar studies in Canada and elsewhere, is to provide such data. The acquisition of such data is not, however, an end in itself, and a recent paper by Hamilton [19], with comments by Bross,

Gardener, Lyon, Johnson and Najarian gives an interesting insight to the complexity that can attend the interpretation of such data. In the context of studies of the health of radiation workers, multiple myeloma is a disease of particular interest. Turesson and his colleagues [20] have described the increasing incidence of multiple myeloma in the United Kingdom and the United States, comparing these data with an already high incidence in Sweden. These authors discuss the significance of improved diagnosis and the possible importance of environmental factors other than radiation exposure. Such factors need to be carefully considered when an assessment is made of an apparent increase in the incidence of a disease in radiation workers.

Epidemiological studies of the health effects of low-level ionizing radiation are now being undertaken in many countries, and there is a need to ensure that those engaged in these studies can enjoy good liason at the international level. This need has been recognized by the International Atomic Energy Agency (IAEA) and a coordinated research program (3038/CF) has been established. The work of this program has been well started and it is to be hoped that it will continue.

8. CONCLUSION

A period of less than four years has elapsed from the formal start of the AECL Employee Health Study in 1980 April to the completion of the first linkage with the Mortality Data Base. During this time a health study data base has been assembled; this consists of up to 32 pieces of information for each of some 14 000 past and current employees, and is stored on magnetic tape.

The immediate task is the analysis, by staff of the Epidemiology Unit of the National Cancer Institute of Canada, of the mortality data emerging from the first linkage referred to above. It is known that this linkage has identified 962* deaths among the study population, and it is not expected that an analysis of these mortality data will provide conclusive information as to the relative importance of the various causes of death. As the study progresses, however, and as data from future linkages augment the mortality data base for the population, the validity of the conclusions will be enhanced within the bounds of the statistical power of the study itself.

Meanwhile, a continuing task will be the improvement of the information available in the study data base.

9. ACKNOWLEDGEMENTS

During the period in which the AECL Employee Health Study was implemented, many people gave generously of their time and advice. The contributions made by the following are gratefully acknowledged:

* linkage weighting > 70

Eldorado Resources Limited: J.D. Abbatt.
AECL, WNRE: D. Booth, I. Brown, D. Lussier, D. Manchulenco, V. Orlick, V. Palson, T. Seifried, A. Walters, C. Wayne, and M. Zach.
AECL, CRNL: J.H. Collins, G. Cowper, J.L. Elder, D.W.S. Evans, M.Hanlon, R.M. Holford, J.R.A. Johnson, C. Lamb, A. Lemke, D.P. Morrison, D.K. Myers, M. Myers, C. Nagy, J.B. O'Byrne, N. Oelke, R. Rondeau, V. Schizkoske, C. Tanner, J. Vincent and M. Werner.
AECL, Corporate Head Office: M. Ferguson and A. Torontow.
AECL, Research Company Head Office: J.A. Schwartz.
Ontario Hydro: T.R. Hamilton.
National Cancer Institute of Canada: G.R. Howe and A.B. Miller.
Statistics Canada: P. Lalonde, A. Mullins and M. Smith.

REFERENCES

1. J.L. Weeks, "A Study of the Health of The Employees of Atomic Energy of Canada Limited: I. Setting up the Study," Atomic Energy of Canada Limited Report, AECL-6813 (1981).

2. S.C. Darby, (Editor), "Protocol for the National Register of Radiation Workers," National Radiological Protection Board, Harwell, U.K., Report NRPB-R-116 (1981).

3. S.A. Fry, A. Rudnick, D.R. Hollis-Hudson, D.M. Robie, C.C. Lushbaugh and C.M. Shy, "Follow-up Study of the Health Experience of the U.S. Department of Energy (DOE) Workers Exposed to $\geq$ 50 mSv (5 rems) Per Year," in Proceedings 3rd International Symposium of the Society for Radiological Protection (U.K.), Inverness, I, 346-351 (1982).

4. John D. Abbatt, T.R. Hamilton and J.L. Weeks, "Epidemiological Studies in Three Corporations Covering the Canadian Nuclear Fuel Cycle," IAEA-SM-266/9, in Proceedings International Symposium Biological Effects of Low Level Radiation, IAEA, Vienna, (1983) (in press).

5. G.J. Briscoe, "Futility of Epidemiological Studies of Radiation Effects," Health Physics 38, 863 (1980).

6. J.L. Weeks, "Epidemiological Studies - A Response," Health Physics, 40, 129 (1981).

7. J.A. Reissland, "Radiation Epidemiology," J. Soc. of Rad. Prot. 3, 29 (1983).

8. A. Linos, J.E. Gray, A.L. Orvis, R.A. Kyle, W.M. O'Fallon, and L.T. Kurland, "Low Dose Radiation and Leukaemia," N. Engl. J. Med. 302, 1101 (1980).

9. J.D. Wang and O.S. Miettinen, "Occupational Mortality Studies: Principles of Validity," Scand. J. Work, Environ. Health 8, 153 (1982).

10. K.F. Baverstock, "Hanford Radiation Study," Brit. J. Ind. Med. 40, 115 (1983).

11. D.K. Myers, M.M. Werner, G. Cowper, D.P. Morrison, and R.M. Holford, "Follow-up of Past Employees of Chalk River Nuclear Laboratories," Proceedings , 3rd International Symposium of the Society for Radiological Protection (U.K.) Inverness, I, 332-39 (1982).

12. M.M. Werner, D.K. Myers, and D.P. Morrison, "Follow-up of CRNL Employees Involved in the NRX Reactor Clean-Up," Atomic Energy of Canada Limited Report, AECL-7760 (1982).

13. M.M. Werner, D.K. Myers, and D.P. Morrison, "Follow-up of AECL Employees Involved in the Decontamination of NRU in 1958," Atomic Energy of Canada Limited Report, AECL-7901 (1982).

14. P.E. Enterline, and G.M. Marsh, "Missing Records in Occupational Disease Epidemiology," J. Occ. Med. Assoc. 24, 677 (1982).

15. D.W. Gau, and A.K. Diehl, "Disagreement Among General Practitioners Regarding Cause of Death, Brit. Med. J. 284, 239-241 (1982).

16. M.R. Alderson, R.I.S. Bayliss, C.A. Clarke, and A.G.W. Whitfield, "Death Certification," Brit. Med. J. 287, 444 (1983).

17. P.E. Enterline, "Attributability in the Face of Uncertainty", Chest, 78 377(August Supplement, 1980).

18. V.P. Bond, "The Radiation Exposure Compensation Act of 1981," Health Physics Newsletter X, 1 (1982).

19. L.D. Hamilton, "Alternative Interpretations of Statistics on Health Effects of Low-Level Radiation," The American Statistician 37, 442 (1983).

20. I. Turesson, O. Zettervall, J. Cuzick, J.G. Waldenstrom and R. Velez, "Comparison of Trends in the Incidence of Multiple Myeloma in Malmo, Sweden and in Other Countries 1950-1979," N. Engl. J. Med. 310, 421 (1984).

APPENDIX A

EMPLOYEE IDENTITY SUMMARY (E.I.S.) FORM AND PERSONAL INFORMATION CONSENT FORM (CURRENT EMPLOYEES)*

*A slightly different form providing space for information on cause of death, where known, was used for past employees.

Atomic Energy of Canada Limited / L'Energie Atomique du Canada, Limitée

EMPLOYEE IDENTITY SUMMARY

RESTRICTED STAFF INFORMATION

SITE -

The following information is required in the interest of Atomic Energy of Canada Limited employees for a health study to help insure that our safety standards are soundly derived.

	PLEASE PRINT
1. SURNAME	
2. ANY OTHER SURNAME(S) YOU MAY HAVE HAD	
3. FIRST GIVEN NAME	
4. SECOND GIVEN NAME	
5. THIRD GIVEN NAME	
6. USUAL NAME OR NICKNAME	
7. SEX	☐ MALE ☐ FEMALE
8. MARITAL STATUS	☐ -SINGLE/WIDOW/WIDOWER ☐ -MARRIED ☐ -OTHER
9. BIRTH DATE	YEAR MONTH (Spell Out) DAY
10. BIRTH PLACE	CITY OR PLACE PROV (or country if not Canada)
11. FATHER'S SURNAME	
12. FATHER'S FIRST NAME	
13. FATHER'S SECOND NAME	
14. FATHER'S BIRTH PLACE	PROVINCE (or country if not Canada
15. MOTHER'S MAIDEN NAME	
16. MOTHER'S FIRST NAME	
17. MOTHER'S SECOND NAME	
18. MOTHER'S BIRTH PLACE	PROVINCE (or country if not Canada)
19. SPOUSE'S BIRTH SURNAME	
20. SPOUSE'S FIRST NAME	
21. SPOUSE'S SECOND NAME	
22. EMPLOYEE NUMBER	
23. SOCIAL INSURANCE NUMBER	
24. PROVINCIAL HEALTH INSURANCE NUMBER	PROVINCE NUMBER
25 SUPERANNUATION NUMBER	
26. STARTING DATE	YEAR MONTH (Spell Out) DAY
27. EMPLOYEE'S ADDRESS	CITY OR PLACE PROV (or country if not Canada)

DIVISION
BRANCH

DATE _____ (YEAR) _____ (MONTH) _____ (DAY)

SIGNATURE _____

Atomic Energy of Canada Limited / L'Energie Atomique du Canada, Limitée

SOMMAIRE D'IDENTITE D'UN(E) EMPLOYE(E)

INFORMATION RESTREINTE - PERSONNEL

ETABLISSEMENT -

LES RENSIEGNEMENTS SUIVANTS SONT REQUIS DANS L'INTERET DES EMPLOYES DE L'EACL. IL S'AGIT, EN EFFET, D'UNE ETUDE SUR LA SANTE DES EMPLOYES QUI NOUS DIRA SI NOS NORMES ACTUELLES DE SECURITE SONT RATIONNELLEMENT ETABLIES.

	EN LETTRES MOULEES SVP
1. NOM DE FAMILLE	
2. NOM(S) DE FAMILLE ANTERIEUR(S)	
3. PREMIER PRENOM	
4. DEUXIEME PRENOM	
5. TROISIEME PRENOM	
6. SURNOM	
7. SEXE	☐ M ☐ F
8. ETAT MATRIMONIAL	☐ -CELIBATAIRE/VEUF/VEUVE ☐ -MARIE(E) ☐ -AUTRE
9. DATE DE NAISSANCE	ANNEE MOIS JOUR
10. LIEU DE NAISSANCE	VILLE PROVINCE (OU PAYS SI NE(E) A L'ETRANGER)
11. NOM DE FAMILLE DU PERE	
12. PREMIER PRENOM DU PERE	
13. DEUXIEME PRENOM DU PERE	
14. LIEU DE NAISSANCE DU PERE	PROVINCE (OU PAYS SI NE A L'ETRANGER)
15. NOM DE JEUNE FILLE DE LA MERE	
16. PREMIER PRENOM DE LA MERE	
17. DEUXIEME PRENOM DE LA MERE	
18. LIEU DE NAISSANCE DE LA MERE	PROVINCE (OU PAYS SI NEE A L'ETRANGER)
19. NOM DE JEUNE FILLE DE L'EPOUSE	
20. PRENOM DU CONJOINT	
21. DEUXIEME PRENOM DU CONJOINT	
22. NUMERO DE L'EMPLOYE(E)	
23. NUMERO D'ASSURANCE SOCIALE	
24. NUMERO D'ASSURANCE-MALADIE PROVINCIALE	PROVINCE NO
25. NUMERO DE PENSION DE RETRAITE	
26 DATE D'ENTREE A L'EACL	ANNEE MOIS JOUR
27. ADRESSE DE L'EMPLOYE(E)	VILLE PROVINCE (OU PAYS SI RESIDENT A L'ETRANGER)

DIVISION -
DEPARTEMENT -

DATE _____ (ANNEE MOIS JOUR) **SIGNATURE** _____

PERSONAL INFORMATION CONSENT FORM

Atomic Energy of Canada Limited is undertaking a long-term study of the health of its employees at all sites. This study has been described in an AECL General Notice issued by Corporate Office, dated 1980 April, a copy of which is available in your Personnel Department office. For the study to be successful, it is important that we be able to precisely identify each employee, and for this reason you are being asked to complete the attached Employee Identity Summary Form. You will note that much of the information required on the Form is information which you were previously required to provide to AECL upon commencing your employment.

For those employees who wish to participate in the study, we would ask that you check the appropriate box on the Consent Form below, complete the Employee Identity Summary and return both documents to your Personnel Department office as soon as possible.

Although AECL is not legally required to comply with the privacy rules outlined in the Canadian Human Rights Act and the Protection of Personal Information Regulations, we believe that protection should be granted to those employees who do not wish any personal information provided by them to be used for the purposes of the study. For these employees, we would ask that you check the appropriate box on the Consent Form below and return the form to the undersigned within 45 days of receipt of this notice. If no response is received from these employees within this time period, it will be assumed that they do not object to the use of their personal information already on file for the purposes of the study.

Please be reminded that none of the information collected and used in the study will be published in a form that could in any way identify any individual employee. Furthermore, all reports issued as a result of the study will be of a statistical nature only. In this way the privacy of each and every employee will be strictly preserved.

J.L. Weeks, M.D., D.I.H.
Director
Health and Safety Division
WNRE,
Pinawa, Manitoba, ROE 1LO

I, _____ consent ☐
do not consent ☐

to the use of personal information provided by me to AECL for the purposes of the study of the health of AECL employees.

Signed _____

Dated _____

HO-354-0

FORMULE DE CONSENTEMENT RELATIVE A

L'UTILISATION DE RENSEIGNEMENTS PERSONNELS

L'EACL a décidé d'entreprendre une étude à long terme concernant la santé de ses employés dans tous les établissements de son ressort. Cette étude a été annoncée dans un avis général de l'EACL publié par le Bureau central en avril 1980. Vous pouvez vous procurer une copie de cet avis général auprès de votre service du personnel. Pour que l'étude porte des fruits, il est important que nous puissions identifier chaque employé(e) avec précision. C'est pourquoi nous vous demandons de bien vouloir remplir la formule ci-jointe qui est un sommaire d'identification. Veuillez noter qu'une grande partie des renseignements demandés dans la formule sont les mêmes que ceux fournis lorsque vous êtes entré(e) à l'EACL.

Les employés désirant participer à l'étude sont priés de cocher la case appropriée de la formule de consentement ci-dessous et de renvoyer cette formule ainsi que le sommaire d'identification dûment rempli à leur service du personnel et, ce, le plus tôt possible.

Bien que l'EACL ne soit pas juridiquement obligée de se conformer aux clauses touchant la vie privée que l'on trouve dans la Loi canadienne sur les droits de la personne et dans les règlements touchant la protection des informations personelles, nous pensons qu'il y a lieu de protéger les employés qui ne désirent pas que les renseignements personnels fournis par eux servent aux fins de cette étude. Nous demandons donc à ces employés de cocher la case négative de la formule de consentement ci-dessous et de renvoyer cette formule au soussigné dans les 45 jours qui suivront la réception du présent avis. Si ces employés ne nous font pas connaître leur refus dans le laps de temps requis, nous considérerons qu'ils ne voient pas d'inconvénient à ce que l'on utilise les renseignements personnels déjà dans les dossiers aux fins de notre étude sur la santé des employés.

Soyez certains qu'aucun renseignement recueilli et utilisé dans cette étude ne sera publié sous une forme qui pourrait identifier la personne l'ayant fourni. De plus, tous les rapports publiés à la suite de cette étude seront exclusivement de nature statistique. De cette façon, la vie privée de chaque employé(e) sera strictement respectée.

J.L. Weeks, M.D., D.I.H.
Directeur
Division Santé et Sécurité
Établissement de Whiteshell
Pinawa, Manitoba, ROE 1LO

Je, _____ consens ☐
ne consens pas ☐

à ce que les renseignements personnels fournis par moi à l'EACL servent aux fins de l'étude sur la santé des employés de l'EACL.

Signature _____

Date _____

APPENDIX B

RADIATION DOSE ENTRY

Radiation doses to the whole body (excluding extremity doses) were entered onto the E.I.S. forms for past employees at CRNL and WNRE. A rubber stamp was devised and used on each E.I.S. form to include information on: any gamma dose, in mrem (1 mrem = 0.01 mSv), beta dose or neutron dose, along with whether the individual was involved in either the 1953 or 1958 cleanups at CRNL and whether a record existed of the individual being internally exposed (indicated by entering "I" on the stamp). Only the gamma doses were entered into the computer; beta doses may be added later if considered necessary. The dose figure includes only exposure prior to and while working for AECL, and does not include doses received at subsequent places of employment.

APPENDIX C

UNIQUE IDENTIFYING STUDY NUMBERS

NUMBER ALLOCATIONS

CURRENT EMPLOYEES:

WNRE — #'s 00001 - 01000

00001 - 00491: Consenters
00492 - 00852: Non-responders
00853 - 00863: Consenters (changed from non-consent)

CRNL — #'s 01001 - 03500

01001 - 02595: Consenters
02596 - 03207: Non-responders
03208 - 03232: Consenters (changed from non-consent)

RESEARCH COMPANY HEAD OFFICE — #'s 03501 - 03700

03501 - 03538: Consenters
03539 - 03540: Non-responders

ENGINEERING COMPANY — #'s 03701 - 07000

03701 - 05345: Consenters
05346 - 06050: Non-responders

RADIOCHEMICAL COMPANY — #'s 07001 - 09000

07001 - 07353: Consenters
07354 - 07756: Non-responders

CHEMICAL COMPANY HEAD OFFICE — #'s 09001 - 09500

09001 - 09068: Consenters
09069 - 09077: Non-responders

GLACE BAY HEAVY WATER PLANT — #'s 09501 - 11000

09501 - 09651: Consenters
09652 - 09858: Non-responders

PORT HAWKESBURY HEAVY WATER PLANT — #'s 11001 - 13000

11001 - 11135: Consenters
11136 - 11277: Non-responders

INTERNATIONAL COMPANY — #'s 13001 - 14000

13001 - 13009: Consenters
13010 - 13014: Non-responders

CORPORATE HEAD OFFICE — #'s 14001 - 15000

14001 - 14097: Consenters
14098 - 14121: Non-responders

PAST EMPLOYEES:

WNRE — #'s 78000 - 79999

78000 - 78859 (actually used)

CRNL — #'s 80000 - 99999

80001 - 86246 (actually used)

APPENDIX D

DATA ENTRY (D.G.N. BOOTH)

An employee health study data base was created by the Data Entry Staff of the WNRE Finance Branch during the period 1981 September to 1983 January. The data base contains over 14 000 records. Each record is 428 characters long and contains the following information: cohort identifier, health study identification number, site identifier, surname and given names, sex, marital status, birth date and place, father's name and birthplace, mother's name and birthplace, spouse's name, employee's badge number and employee number, social insurance number, health insurance number, superannuation number, period(s) of employment, address, radiation-exposure information, death date and place, last year known alive.

The data were obtained from Employee Identity Summary (E.I.S.) forms (Appendix A). The forms were completed by the personnel departments in the case of terminated employees and personally by those who were still employed.

The process of setting up the data base involved a sizeable data entry job, which was accomplished by integrating the work with the normal data entry workload of the Finance Branch. The work was completed over a 16-month period and was performed by five data-entry/computer operators. To eliminate any keying errors the data were also key-verified.

The work was subdivided into groups of 100 E.I.S. forms. This provided a means of controlling the forms and scheduling the work. Once the data-entry/verification function was completed, the operators produced a listing of the data in the group. To further improve the quality, the listing was site checked by WNRE Health and Safety Division personnel. Corrections were made where necessary and a new listing produced.

Once the data were deemed valid and complete by the Health and Safety Division, the E.I.S. forms were filed and the data corresponding to that group were transferred to the health study data base. Computer programs were developed to handle this process and backup/restore procedures were also developed to protect against accidental loss of data.

Procedures were also established to produce tape copies of the data base for use by Statistics Canada, CRNL and WNRE.

APPENDIX E

MEDICAL AND LIFESTYLE QUESTIONNAIRE AS DISTRIBUTED*

*Egalement disponible en langue francaise.

WE WOULD LIKE TO KNOW ABOUT YOUR HEALTH AND THAT OF YOUR FAMILY

1. We would like to ask you about some common diseases and medical conditions that you may have had during your life.

Please look at the list below and put a ✓ mark opposite any condition that you have been diagnosed as having had. Also, please give us your approximate age when you were first diagnosed with the condition.

	Check if had	Age		Check if had	Age
HYPERTENSION (HIGH BLOOD PRESSURE)	☐		THYROID PROBLEMS	☐	
DIABETES	☐		CIRCULATORY AILMENTS	☐	
TUBERCULOSIS	☐		RHEUMATISM/ARTHRITIS	☐	
STOMACH ULCER	☐		GALL BLADDER PROBLEMS	☐	
STROKE	☐		ANEMIA	☐	
LEUKEMIA (CANCER OF THE BLOOD)	☐				

HEART DISEASE ☐ Age: ____

If you have had heart disease, please tell us what type of heart disease you have had:

_____

_____

CANCER ☐ Age: ____

If you have had cancer, please tell us what type of cancer you have had:

_____

_____

2. Have any of your blood relatives ever been diagnosed with cancer? (This would include your mother, father, brothers, sisters, grandparents, uncles, cousins, etc.)

Please check the appropriate box:

Yes ☐ No ☐

If any of your blood relatives have ever been diagnosed with cancer please tell us which of your relatives this was and what type of cancer it was:

Relative	Type of Cancer

3. Please look at the list below and put a ✓ mark opposite any of the types of x-ray examinations you may have had during your life.

For each type of x-ray examination you may have had please tell us approximately how many you have had during your life.

	Check if had	Approximate number
1. DENTAL X-RAYS	☐	☐☐☐
2. CHEST X-RAYS	☐	☐☐☐
3. SKULL X-RAYS	☐	☐☐☐
4. ABDOMEN: UPPER G.I. SERIES (BARIUM MEAL)	☐	☐☐☐
5. ABDOMEN (BARIUM ENEMA)	☐	☐☐☐
6. ABDOMEN INTRAVENOUS PYELOGRAM (X-RAY OF KIDNEYS)	☐	☐☐☐
7. ABDOMEN GALLBLADDER SERIES	☐	☐☐☐
8. ARMS/HANDS	☐	☐☐☐
9. LEGS/FEET	☐	☐☐☐
10. BACK/SPINE	☐	☐☐☐

4. Have you ever received radiation <u>treatment</u> for any disease?

Please check appropriate box

Yes ☐ No ☐

If you have ever received radiation <u>treatment</u> for any disease, please tell us what the disease was and your age when you first were given this treatment:

Disease	Age

WE WOULD LIKE TO KNOW ABOUT SOME JOBS YOU MAY HAVE WORKED AT DURING YOUR LIFE

5. We would like to ask you about some substances that you may have come in contact with while working in some of the jobs you may have had.

Please look at the list below and put a ✓ mark opposite any substance you have been in contact with while at work. If you have had contact with the substance please tell us the type of job or jobs involved, the year you first worked in that job, and the year you last worked in that job.

	Yes		Jobs	Year Started	Year Ended
1. BENZENE	☐	1.		19	19
		2.		19	19
2. ASPHALT (OR TAR)	☐	1.		19	19
		2.		19	19
3. CHLORINATED COMPOUNDS SUCH AS CARBON TETRACHLORIDE, CHLOROFORM	☐	1.		19	19
		2.		19	19
4. ASBESTOS	☐	1.		19	19
		2.		19	19
5. PETROLEUM PRODUCTS OR OTHER ORGANIC CHEMICALS	☐	1.		19	19
		2.		19	19

Please look at the list below and put a ✔ mark opposite any substance you have been in contact with while at work. If you have had contact with the substance please tell us the type of job or jobs involved, the year you first worked in that job, and the year you last worked in that job.

	Yes		Jobs	Year Started	Year Ended
6. COKE FUMES	☐	1.		19	19
		2.		19	19
7. HERBICIDES, FUNGICIDES, AND PESTICIDES	☐	1.		19	19
		2.		19	19
8. METALS AND METALLIC COMPOUNDS SUCH AS ARSENIC OXIDES, LEAD COMPOUNDS, ZINC CHROMATE COBALT	☐	1.		19	19
		2.		19	19
9. URANIUM (EG. MINING OR PROCESSING)	☐	1.		19	19
		2.		19	19
10. RADIATION SUCH AS INDUSTRIAL X-RAYS	☐	1.		19	19
		2.		19	19

WE WOULD LIKE TO KNOW ABOUT SOME GENERAL LIFESTYLE HABITS

6. Have you ever smoked cigarettes regularly? That is, have you ever smoked at least 1 cigarette per day for a period of at least six months. Please check the appropriate box:

No ☐ Yes ☐

(If you have never smoked cigarettes regularly please go on to Question 7)

At what age did you start smoking cigarettes regularly? Age ____

On average how many cigarettes a day do/did you smoke? Number ____

If you have quit smoking cigarettes, how many years has it been since you last smoked regularly? Years ____ Months ____

When you smoke (or smoked) cigarettes regularly, what kind of cigarettes did/do you usually smoke? Please check the appropriate box below:

- Usually Filter ☐
- Usually Plain ☐
- About the same filter and plain ☐

When smoking cigarettes, to what extent do you/did you usually inhale? Please check the appropriate box below:

- Deeply ☐
- Somewhat ☐
- Not at all ☐

7. Have you smoked pipes regularly? That is, have you ever smoked at least 1 pipeful per day for a period of least six months? Please check the appropriate box.

No ☐ Yes ☐

(If you have never smoked pipes regularly please go on to Question 8)

At what age did you start smoking pipes regularly? Age ____

On average how many pipefuls do you/did you smoke per day? Number ____

If you have quit smoking pipes, how many years has it been since you last smoked regularly? Years ____ Months ____

When you smoke (or smoked) pipes regularly, to what extent do you/did you inhale? Please check the appropriate box at right

- Deeply ☐
- Somewhat ☐
- Not at all ☐

8. Have you ever smoked cigars regularly? That is, have you ever smoked at least one cigar a day for a period of at least six months? Please check the appropriate box:

No ☐ Yes ☐

9. Have you ever consumed alcoholic beverages regularly? That is, have you ever drank beer, wine, or liquor at least once a day for a period of at least six months. Please check the appropriate box opposite:

No ☐ Yes ☐

(If you have never drank alcoholic beverages regularly please go to Question 10)

On average, how many drinks of the following do you/did you consume per day?

- WINE — Number of Glasses ____
- BEER — Number of Bottles/Cans ____
- LIQUOR (RYE, GIN, RUM, ETC.) — Number of Drinks ____

10. Please fill in the date on which you completed this questionnaire: Day ____ Month ____ Year ____

THANK YOU
FOR TAKING PART
IN THE STUDY

APPENDIX F

COVERING LETTER FOR MEDICAL AND LIFESTYLE QUESTIONNAIRE*

*Egalement disponible en langue francaise.

FACULTY OF MEDICINE
DEPARTMENT OF PREVENTIVE MEDICINE
AND BIOSTATISTICS
UNIVERSITY OF TORONTO
TORONTO, CANADA
M5S 1A8

DEAR

As you may know Atomic Energy of Canada Limited is undertaking a major long-term study of the health of its employees. This study is being carried out in collaboration with ourselves at the Department of Preventive Medicine and Biostatistics of the University of Toronto. We are acting as advisors to AECL for this study, and in particular we will be responsible for anlyzing the results.

In order to learn as much as possible from this study, and thus be of most help to both present and future employees of AECL we are writing to ask you for your further help. Enclosed is a questionnaire about some medical, occupational and life style factors which may affect an individual's health. We would like you to fill in this questionnaire and return it to us at the Department of Preventive Medicine in the stamped addressed envelope supplied.

You will see that the questionnaire does not ask for your name. This is in order to ensure confidentiality. You will also notice that the questionnaire contains a printed number, provided by AECL and this number does refer specifically to you. However, we do not know which individual that number refers to, and the information you give us will under no circumstances be released to AECL. The data will be linked through the number to the other information we will receive and will be analyzed purely as statistical records.

You are under no obligation to fill in the questionnaire. Nobody (including AECL) will know who did or did not complete and return a questionnaire. However, the more people who help us the more reliable the results of the study will be. Every effort has been made to ensure that this questionnaire is sent only to those employees who have not indicated that they do not wish to take part in the study. If you have already indicated that you do not wish to take part please disregard this letter.

This is an opportunity to help yourselves and your fellow employees. The information you provide will also make a very valuable contribution to medical research in general. We are therefore most grateful for your help.

Thank you very much for your cooperation.

Yours sincerely,

G.R. Howe, PhD
Professor

A.B. Miller, MB, FRCP(C)
Professor

PLEASE DO NOT RETURN THIS LETTER WITH THE QUESTIONNAIRE

FORM 3, AEC

ISSN 0067-0367

To identify individual documents in the series we have assigned an AECL- number to each.

Please refer to the AECL- number when requesting additional copies of this document from

Scientific Document Distribution Office
Atomic Energy of Canada Limited
Chalk River, Ontario, Canada
KOJ 1JO

Price: $4.00 per copy

ISSN 0067-0367

Pour identifier les rapports individuels faisant partie de cette série nous avons assigné un numéro AECL- à chacun.

Veuillez faire mention du numéro AECL - si vous demandez d'autres exemplaires de ce rapport au

Service de Distribution des Documents Officiels
L'Energie Atomique du Canada Limitée
Chalk River, Ontario, Canada
KOJ 1JO

prix: $4.00 par examplaire