

C.1

OCCUPATIONAL NOMINAL ROLL INFORMATION AS A DATA BASE FOR  
EPIDEMIOLOGICAL RESEARCH: CASE STUDY AND POLICY OPTIONS

by

VALERIE C. EMBREE

B.A., University Of British Columbia, 1974

A THESIS SUBMITTED IN PARTIAL FULFILMENT OF  
THE REQUIREMENTS FOR THE DEGREE OF  
MASTER OF SCIENCE

in

THE FACULTY OF GRADUATE STUDIES  
Health Services Planning Program

We accept this thesis as conforming  
to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA

May 1983

© Valerie C. Embree, 1983

In presenting this thesis in partial fulfilment of the requirements for an advanced degree at the University of British Columbia, I agree that the Library shall make it freely available for reference and study. I further agree that permission for extensive copying of this thesis for scholarly purposes may be granted by the Head of my Department or by his or her representatives. It is understood that copying or publication of this thesis for financial gain shall not be allowed without my written permission.

Department of Health Care & Epidemiology

The University of British Columbia  
2075 Wesbrook Place  
Vancouver, Canada  
V6T 1W5

Date: 27 April 1983

Abstract

Evaluation of delayed health effects of work environments, or occupational health research, has become of increasing social concern. This is partly due to the question of social justice for workers harmed by unrecognized hazards and to the appreciation that many public environmental pollutants are a diluted form of a problem in the workplace where they originate and therefore are more easily identified and assessed in the occupational setting.

Epidemiology is a tool for investigating causes of disease and impact of suspected hazards in human populations. A basic requirement for epidemiological research is an identifiable population for whom an inference of exposures to potential hazards can be made. In occupational health research this is often an occupational nominal roll, or list of people employed in a particular occupation or work site.

This paper examines employment records in the British Columbia coastal lumber industry in an attempt to evaluate the quality of historical employment records as a data base for epidemiological research. The criteria against which they will be evaluated are those of Statistics Canada, which maintains outcome information in the form of death and cancer records. Issues of confidentiality in relation to record retention and linkage are discussed. Mechanisms and policy options for improving the fit between employment records and research needs are presented.

# Table of Contents

Abstract .....	ii
List of Tables .....	v
Acknowledgements .....	vi
I. EPIDEMIOLOGY, OCCUPATIONAL DISEASE, AND RECORD LINKAGE .....	1
A. INTRODUCTION .....	1
B. EPIDEMIOLOGY AS AN OCCUPATIONAL HEALTH RESEARCH TOOL .....	1
C. EPIDEMIOLOGY: ITS CONCEPTUAL FRAMEWORK AND A CRITIQUE .....	9
D. OCCUPATIONAL INJURY AND DISEASE AS A SOCIAL ISSUE .....	13
E. RECORD LINKAGE .....	17
II. NOMINAL ROLL DATA BASE CASE STUDY .....	24
A. INTRODUCTION .....	24
B. THE CASE STUDY AS A RESEARCH METHOD .....	25
C. CASE STUDY .....	27
D. RECORDS .....	30
1. UNION RECORDS .....	30
2. COMPANY RECORDS .....	32
a. Personnel Records .....	32
b. Payroll Records .....	33
c. Other Records .....	34
E. SECONDARY DATA SOURCES .....	35
1. IWA/FOREST INDUSTRY PENSION PLAN .....	35
2. IWA/FOREST INDUSTRY HEALTH AND WELFARE PLAN .....	37
F. EXPOSURE HISTORIES .....	38
G. GOODNESS OF FIT .....	41
III. POLICY ISSUES AND OPTIONS .....	44
A. IMPROVING THE FIT: POSSIBLE MECHANISMS .....	44
1. FEDERAL AND PROVINCIAL LABOUR LEGISLATION .....	47
2. OCCUPATIONAL HEALTH AND SAFETY REGULATIONS .....	50
3. COLLECTIVE AGREEMENTS .....	54
4. CONCLUSION .....	56
B. THE CONFIDENTIALITY ISSUE .....	57
1. PRIVACY AND CONFIDENTIALITY AS AN ISSUE .....	57
2. SOME DEFINITIONS .....	60
3. INDIVIDUAL VERSUS PUBLIC INTERESTS .....	62
4. SIGNIFICANCE OF MICROELECTRONIC TECHNOLOGY .....	64
5. THE UNIQUE PERSONAL IDENTIFIER ISSUE .....	68
6. SOME PROPOSALS FOR SOLUTIONS TO THE TECHNOLOGY PROBLEMS .....	70
7. SPECIAL ISSUES RELATING TO EMPLOYER-HELD RECORDS .....	74
8. GUIDELINES FOR A BALANCING OF INTERESTS .....	80
C. POLICY OPTIONS .....	85
1. THE COLLECTIVE BARGAINING ARENA .....	86
2. THE LEGISLATIVE AND REGULATORY ARENA .....	89
3. POLICY OPTIONS: CONCLUSION .....	94
BIBLIOGRAPHY .....	95

APPENDIX A - EPIDEMIOLOGY: DEFINITIONS, HISTORY, METHODS AND CRITIQUE .....	103
APPENDIX B - OCCUPATIONAL INJURY AND DISEASE: DIMENSIONS OF THE PROBLEM .....	117
APPENDIX C - OCCUPATIONAL HEALTH AND SAFETY - ECONOMIC THEORY .....	121

List of Tables

I.	List of Items to be Included in an Employee Health- identifying Questionnaire .....	23
II.	B.C. Coast Lumber Industry: Identifying Information Available .....	42

Acknowledgement

I extend my thanks to family, friends, fellow students, co-workers and teachers who provided support and encouragement while this work was in process. In addition, I appreciate the members of Community Alternatives Society and particularly my partner John for involving me in an intensity of living during the last few years which kept this work in some perspective.

## I. EPIDEMIOLOGY, OCCUPATIONAL DISEASE, AND RECORD LINKAGE

### A. INTRODUCTION

The purpose of this chapter is to familiarize the reader with epidemiology as an approach to occupational disease research, with occupational hazards as a social issue, and with the significance of record linkage for research.

### B. EPIDEMIOLOGY AS AN OCCUPATIONAL HEALTH RESEARCH TOOL

Epidemiology is the study of the distribution and determinants of disease frequency in human populations.<sup>1</sup> It is a basic tool of medical research (Holland and Karhausen, 1978). Its roots are in the public health movement and the application of quantitative reasoning in the study of disease in the mid-nineteenth century in Britain and France (Lilienfeld and Lilienfeld, 1980). The early focus of epidemiology on infectious diseases has shifted, as has public health practice itself, to include the detection and evaluation of environmental hazards<sup>2</sup> and evaluation of the effectiveness of medical services themselves (Friedman, 1974).<sup>3</sup>

Epidemiological investigations are of three general types:

---

<sup>1</sup> This is a minor adaptation of the frequently quoted definition provided by MacMahon and Pugh, 1970, which states: "Epidemiology is the study of the distribution and determinants of disease frequency in man."

<sup>2</sup> Including: exposure to land, air and water pollutants; lifestyle factors such as smoking, diet, activity; and medical diagnostic and treatment regimes themselves, such as drugs or radiation.

<sup>3</sup> See Appendix A for a more extensive description of epidemiology as a discipline.



descriptive, analytic and experimental. Descriptive studies are often the approach chosen to examine new problems, and generally gather together existing data on who is affected, what disease (or exposure) is of concern, when the disease (or exposure) occurs and where it occurs, noting differences in frequency among locations. A descriptive study should provide an information base from which to begin to generate theories about why the condition in question occurs (or whether there are patterns of problems which should be investigated further in relation to an exposure).

Analytic studies test hypotheses about disease causation by determining the strength of associations between variables, for example, between the presence of a disease and history of a particular exposure.<sup>1</sup> These studies are "natural experiments"; that is, people are located who have a particular characteristic and then studied to see if they have the hypothesized linked characteristic. When the population is identified on the basis of presence or absence of exposure (usually the hypothesized cause) and then investigated to see if the outcome or effect predicted (e.g. a particular disease) occurred, the type of investigation is called a cohort study.

When the population is identified on the basis of presence or absence <sup>2</sup> of an outcome (or effect, such as a disease) and

---

<sup>1</sup> E.g. epidemiological studies demonstrated a strong association between lung cancer and a history of heavy cigarette smoking.

<sup>2</sup> Note: the population selected for absence of the exposure (in cohort studies) or absence of the outcome (in case-control studies) are referred to as "controls" in both kinds of studies.

then investigated for history of exposure to the hypothesized cause, the study is called a case-control study.

Cohort studies select a population on the basis of exposure (usually hypothesized cause) and investigate the extent of the predicted effect, or outcome. Case-control studies select a population on the basis of outcome (usually a disease of concern) and investigate the extent of exposure to the hypothesized cause(s).

A determination of causation from analytic studies is a matter of judgement based on a number of factors , including the statistical strength of the association, the consistency of the association over repeated studies, the specificity of the association, and its biological plausibility. (Fox et al., 1970; MacMahon and Pugh, 1970)

Experimental studies involve intervention on the part of the researcher to introduce, modify or reduce a risk factor and evaluate the effect. This is usually a research design option in the evaluation of health services, such as education or screening programs, or in clinical trials of new treatment or drug regimes.

For a fuller discussion of epidemiological research designs, see Appendix A.

Some of the major difficulties of epidemiological studies and their results arise from information inadequacies (for example, completeness and accuracy of exposure records or

diagnosis and/or cause of death records)<sup>1</sup>, validity of participant selection (e.g. avoiding self-selection, or volunteer bias; selecting a meaningful comparison group), anticipation of potential confounding variables, and adequate resources (Sources for this discussion are Elwood and Elwood, 1980; Siemiatycki et al., 1981; Calkins et al., 1980).

A great deal of control over completeness and accuracy of information is possible with studies where data collection occurs after the study has been designed; however, these are fairly rare events and do not offer much immediate assistance to the problems of workers exposed historically to potential hazards, especially where the latency period of the diseases of concern may be two or three decades. More common is the study using already existing records, which usually have been generated for other purposes (e.g. payroll, medical plan payment). In these studies, the limitations may be profound

---

<sup>1</sup> It is important to recognize that the contents of records are influenced by many factors, a good number of which may be unknown to the secondary user. For example, employers' job lists in the coastal lumber industry may use a job title "puller". This job category may encompass positions on production lines carrying chemically treated lumber and lines carrying untreated lumber. The job record masks what may be an important difference in exposure, yet there may be no better way to establish exposure histories than on the basis of existing job categories. Another example is that of inaccurate diagnosis or treatment records made by physicians, sometimes for the explicit purpose of ensuring confidentiality to their patient. This phenomenon has been widely discussed in reviews of suicide rates and international patterns of reporting. These examples are given only to illustrate that in any record system, there may be patterns of distortion or ambiguity that have a rationale unrelated to the apparent record keeping purpose. Any systematic distortion of this nature will of course reduce the validity of epidemiological research which relies upon existing records.

(e.g. only last occupation may be recorded in a medical record and then, perhaps not specifically enough to be useful in clarifying exposures). These disadvantages are the non-economic costs of the otherwise relatively inexpensive and efficient approach to epidemiological research that routine record analysis provides.

Where interviewing supplements record search, systematic bias may be a factor in recall of information (participants exposed to a particular hazard or suffering from the disease or condition under investigation may remember or report events differently than participants not exposed or not suffering from the disease or condition of concern). In other words, the participants may not be blind to the research hypothesis and this may result in reporting or recall bias.

Unintended bias in selection of comparison groups (e.g. a group exposed to a particular hazard and a group unexposed, or a group with a particular disease or condition and a group from the same population without the disease or condition) is another major source of weakened results in epidemiological studies. It is never possible to analyze the comparability of the populations on all potentially relevant factors, even if intensive interviewing were included. Effective methods for selection of comparable groups will vary depending on the specific characteristics of the situation; common options include selection on the basis of geographic or time proximity (e.g. neighbor, next hospital admission), another working population without the exposure of concern, or specific

alternative disease(s) registered at the same time.

Finally, resources available for epidemiological research are tiny in comparison to the occupational health problems needing to be addressed (see also discussion below and Appendix B). There are severe shortages of trained epidemiologists (Detels, 1978) and economists point out that in a free market economy, there are real economic disincentives for generation of information (Manga, et al. 1981). Since the tasks of generating, assembling and processing information is complex and hence costly, and since the decision based on that information is likely to be the same across interested individuals, it is inefficient for any one individual to generate the information (i.e. contrary to any individual's self-interest). There are a variety of sources of "market failure", meaning that an unregulated economy ("free market" or neo-classical model) will not by itself allocate sufficient resources to occupational disease prevention and compensation (Reschenthaler, 1979; Economic Council of Canada, 1981; Manga et al., 1980).<sup>1</sup>

As a result, occupational epidemiological research is usually funded by public money. However, competition for the public dollar is severe, hence the problem of inadequate resources.

In reaching an understanding of the role of epidemiology in occupational health research, it may be useful to examine briefly the strengths and weaknesses of other scientific methods

---

<sup>1</sup> For further discussion of this issue, see Appendix C.

of hazard assessment, for example, in vitro and in vivo (animals) assessment of industrial chemicals for carcinogenicity.

The attractiveness of animal and in vitro studies for assessment of cancer risk to humans is clearly related to the radically shortened time frame required for assessment and avoidance of subjecting humans to experimentation. However, there is also much resistance to regulating chemical use in industry based solely on non-human data. The assumptions behind extrapolating from animal testing to humans are reported by Schottenfeld and Haas (1978) as:

- chemicals that cause cancer in one or more mammalian species may be capable of causing cancer in humans;
- the dose-response curve assumed for human beings may be analagous to that demonstrated in the most sensitive animal model;
- although it is conceivable that at certain dose levels even potent carcinogens will not produce tumours in humans, a subthreshold dose or "safe" level cannot be determined with certainty by animal assays (author's note: nor can latent periods at particular dose levels be determined for humans);
- higher dose levels of a chemical carcinogen may increase the incidence of cancers, or of the number of primary cancers per animal, or shorten the latency period;
- target organs for tumour(s) observed in experimental animals may not necessarily predict the type(s) of

tumour in humans (author's note: lack of carcinogenic response in animals does not completely rule out the possibility of carcinogenicity in humans).

The most controversial issues raised by animal tests however are the questions of appropriateness of high dose testing, and interpretation of conflicting data from different species. Calkins et al. (1980) state that a consensus is emerging on these questions. They state that high dose testing is necessary to limit time and number of animals required. They state that such dose levels do not imply that similar dose levels for humans are required to establish carcinogenicity.<sup>1</sup>

With respect to divergent results, Calkins et al. (1980) state that the consensus emerging is "to let positive results supersede negative results in tests involving different species", given that appropriate testing procedures have been followed in both.

In vitro tests for mutagenicity, variously called short-term screening tests, or in vitro assay systems, correlate well with carcinogenicity (McCann and Ames, 1976; Calkins et al., 1980), and have the advantage of being even cheaper and quicker than animal studies. However, no in vitro test is 100 per cent sensitive or specific and Calkins et al. (1980) therefore

---

<sup>1</sup> This issue is addressed somewhat more irreverently by two journalists quoted by Epstein (1978), p. 54: "The bottom line on carcinogenesis testing is this. You can drown an animal in a pool of some substance, suffocate an animal under a heap of it, or beat an animal to death with a sock full of it, but if it isn't carcinogenic, you can't give an animal cancer with it."

recommend in vitro tests as screening tests only, most useful for establishing priorities for animal and/or epidemiological testing.

It can be seen from the above discussion that the limitations of epidemiology and in vivo/in vitro testing are to a large extent complementary. Epidemiology has the strength of dealing with human subjects; its weaknesses are the (usually) long time periods required to see results (effects), relatively high costs for precise work and the difficulty in completely isolating variables. The in vivo/in vitro studies are low cost and quick in comparison and can readily isolate variables and dose levels. However, extrapolation of results to humans remains controversial, partly due to variation in response among species and interpreting the significance of dose levels.

Hazard assessment can obviously take advantage of all three approaches, with people working in any of these methods alerting colleagues to new findings in their own area and using results from other disciplines to suggest new research areas in their own discipline.

### C. EPIDEMIOLOGY: ITS CONCEPTUAL FRAMEWORK AND A CRITIQUE

Epidemiology, as a branch of medicine generally, has traditionally functioned from the same conceptual framework, or paradigm, as has clinical medicine. Mishler (1981) describes the conceptual framework as the biomedical model of illness. Peterson (1981) and Chalmers (1982) describe it as a positivist theoretical approach.



Mishler (1981) states there are four assumptions inherent in the biomedical model:

- i. the definition of disease as deviation from normal biological functioning;
- ii. the doctrine of specific etiology (i.e. that each disease has a specific pathogenesis and pathology);
- iii. the assumption of generic diseases (i.e. "that each disease has specific and distinguishing features that are universal to the human species. That is, disease symptoms and processes are expected to be the same in different historical periods and in different cultures and societies.")
- iv. the scientific neutrality of medicine (i.e. that medicine "has adopted not only the rationality of the scientific method but the concomitant values of the scientist, namely, objectivity and neutrality. ... the implication [is] that the work ... is guided primarily by 'objective' scientific rules and criteria and therefore is relatively unaffected by wider social, cultural, and political forces.") (quotations from Mishler, 1981)

Epidemiology relies upon this conceptual framework for definition of its problems, design of studies and interpretation of findings according to Mishler. As a result, even though

epidemiology's investigation of the health of populations and communities contrasts with clinical medicine's focus on individual patients and cure of specific diseases, epidemiology is severely limited in its handling of social and cultural factors. They are used "essentially as indicators of situations that increase or decrease biological risk factors" (Mishler, 1981). Although epidemiology's "search for social correlates of illness falls outside the boundaries, or at least stretches the limits of the biomedical model", as Mishler states, "epidemiology does not offer an alternative to the biomedical model either in its definition of illness or in its theory of disease causation."

Both Paterson (1981) and Chalmers (1982) argue that the positivist approach can lead only to "superficial" findings, that is, can describe, but cannot finally explain the phenomenon under investigation. The structural relationship of factors associated with disease (including disease definition itself) is not investigated as a causal factor, i.e. as an underlying cause. For example, social class is not pursued as a potential cause of disease in and of itself. Instead, as Mishler has noted, when social and cultural factors are included as variables in epidemiological investigation they are used to locate specific populations at risk or to isolate certain disease-producing conditions, which then permits more direct tests of biologically grounded etiological hypotheses. Mishler offers "constructivism" or "social constructivism" as an alternative model. He describes this theoretical framework as a

major tradition of sociological thought, proposing that "reality is constructed through human action, and does not exist independently of it. ... the world as a meaningful (emphasis in original) reality is constructed through human interpretive activity."

The significance of this approach for epidemiological investigation is stated by Mishler as follows:

... The work of physicians and other health professionals is understood as integral to the definition and diagnosis of disease, and hence in its production. ... their beliefs and practices with regard to diagnosis and treatment are topics of inquiry and require further analysis and interpretation. Therefore, the focus of investigation shifts from patients' symptoms as criteria for the diagnosis ... to the ways in which such criteria are applied, to institutional factors that affect clinical practice ... and to broader socio-cultural forces and values that influence the choice and use of particular criteria." (Mishler, 1981. p. 163)

Chalmers (1982) limits his discussion of alternatives to positivism in epidemiology to a call for a scientific revolution (in a Kuhnian sense, that is a significant shift in the dominant paradigm, or conceptual framework.<sup>1</sup>). Chalmers proposes that such a revolution might consist of a shift from the concept of individualism (i.e. individuals as free agents, choosing lifestyles, making decisions about social institutions, etc.) which "permeates the modern conception of the social world" to a concept of class as a level of analysis in epidemiology.

---

<sup>1</sup> See Kuhn, T.S. The Structure of Scientific Revolutions, Chicago: University of Chicago Press, 1970.

The implications of traditional epidemiology's reliance upon the postivist/biomedical paradigm are, according to Mishler, that the social contexts of patients and their illnesses have been neglected, with the result that social meanings of illness go unaddressed by the biological sciences. This in turn results in a limitation in both the understanding and treatment of disease by medical practitioners. He argues that when illness is seen as socially produced, a wider range of information and interests must be taken into account than is required by the biomedical model. He states that although this can be seen as a threat to medical authority and the status and power that are the accompaniments of medical dominance, it also implies that patients and others are potential allies of physicians in affecting the process of labelling, diagnosis, management and treatment of illness and therefore in providing more humane and socially responsive care. He suggests that, given a larger conceptual framework, clinical practice could be returned to its social context, turning away from the medicalization of life and towards the resocialization of medicine. (A more extended discussion appears in Appendix A.)

#### D. OCCUPATIONAL INJURY AND DISEASE AS A SOCIAL ISSUE

The 1970's have seen increasing public concern about the rates of injury and disease attributable to the workplace. Manga et al. (1981) report that more than one million cases of occupational disease, injury or fatality are reported annually to Canadian workers' compensation boards. Compensation costs

totalled nearly one billion dollars in Canada in 1978, not including indirect costs to employers (e.g. work disruption, damage, replacement hiring and training, drop in worker morale and possible legal fees) and the injured worker and his/her family (e.g. loss of full pay, loss of self-esteem, pain and suffering, including family stress, sometimes culminating in marital and family breakdown, with the potential for social welfare costs resulting). Educated guesses of the hidden costs of occupational injury and disease range from 3.5 to 5 times direct costs (Manga et al., 1981).

Occupational disease (as distinct from injury) claims are the small minority of all claims made to workers' compensation systems.<sup>1</sup>

It is argued that compensation records may seriously underreport occupational disease in particular, primarily due to the generally long latency periods, lower likelihood (than occupational injury) that the worker, the employer or medical personnel will connect the disease outcome with a workplace exposure, and high workforce mobility.

Cancers originating from workplace exposures generate perhaps the strongest public concern. This may partly be due to the role of cancer in contemporary social mythology (see Sontag, 1978) but is also due to social justice issues associated with

---

<sup>1</sup> Ashford (1976) cites U.S. Bureau of Statistics figures, 1971-2, of disease claims as five percent of total claims. Ison (1978), investigating three provincial compensation boards in Canada, reports occupational disease claims (excluding loss of hearing) were only 0.8 to 1.7 percent of permanent disability awards in 1976.

occupational disease. For example, diseases of an occupational origin are not evenly shared by everyone in society, or even by all paid workers. Also, establishing exposure levels, and therefore the level of risk of disease in a particular workplace, is not within the control of the workers at risk. Higginson (1976) points out that although people may accept high levels of risk in activities in their private lives (e.g. smoking, parachuting, mountain climbing), most people "demand a much higher degree of safety for risks outside their control".

Estimates of the proportion of all cancers caused by occupational exposures is generally between one and ten percent (Higginson, 1976; Wynder and Gori, 1977; Doll, 1977) but ranges to at least twenty percent (U.S. National Cancer Institute, 1978<sup>1</sup>). Cancers of an occupational origin are accorded an importance beyond their numbers by scientists as well as the public partly because of the social justice issues mentioned above, and partly because industrial chemicals often move into the general environment, intentionally or unintentionally, resulting in exposure of potentially very large populations. These hazards to the public which are generated by firms, but which are not part of production costs, are known as an externalities factor in market failure. Although exposures in the general environment may be much less than industrial exposures, Richard

---

<sup>1</sup> "National Cancer Institute/NIEHS Draft Summary Report on the Incidence of Cancer from Occupational Factors", Occupational Safety and Health Reporter, 8, 1978, 1090-1; in Manga et al., 1981.

Doll (1977) states that risks of even minute doses cannot be dismissed:

... we can no longer assume that thresholds<sup>1</sup> exist for chemical or physical agents and we ought neither to ignore nor to condemn them until we have derived quantitative relationships between the dose to which individuals are exposed and the resultant incidence of the disease. At present we can do this only very crudely.

The importance of occupational diseases then is partly due to the signal they offer for the identification of hazards as a result of the "high risk" situation, and therefore intervention for prevention. Any quantitative information obtainable from industrial exposures, though not immediately interpretable to lower dosage general environmental exposures, at least is a potential alert. (See Appendix B for a fuller discussion of occupational injury and disease as a social issue.)

---

<sup>1</sup> With respect to thresholds, standards of exposure (threshold limit values) of less than 500 chemicals have been promulgated in the USA (Schottenfeld and Haas, 1978). Sullivan and Barlow (1979) state that "with the possible exception of ionizing radiation, there have been no systematic studies of the relative safety of the accepted threshold limit values (TLVs) with respect to reproductive hazards. Where evidence of adverse effects on male and female sexual function or reproductive capacity does exist, it has largely been ignored in the setting of TLVs." They state further "It is interesting that TLVs in the USSR are generally set at much lower levels than in the West since they are based on minimal behavioral effects detectable in experimental animals rather than on more conventional measures of acute toxic effects." Sullivan and Barlow (1979) also report that a review of Index Medicus 1960-76 turned up 108 papers from East Europe on possible reproductive hazards in the workplace. Only 68 papers on the topic were reported from the rest of the world. They note that a Russian report in 1967 was the first to draw attention to the poor reproductive outcomes of female anesthetists. They state however that concern over reproductive hazards is now increasing in the West.

## E. RECORD LINKAGE

The purpose of this paper is to address only one aspect of the informational inadequacies facing the occupational health epidemiologist, that is the exposure side, via employment records, of the information equation. Before examining the status of employment records in one industry (in chapter 2), the concept of record linkage and criteria for creation of occupational nominal roll files, as proposed by the Occupational and Environmental Health Research Unit, Statistics Canada, will be reviewed.

The idea of linking recorded information about an individual from one point in time with recorded information on the same individual from another point in time is the fairly simple concept underlying record linkage. Record linkage is usually the term used when referring to the linking of large numbers of records, usually assisted by computer technology. Smaller increases in risks are detectable than ever before as a result of computer technology's ability to link large numbers of records cheaply and accurately. Of particular significance is the ability, as Acheson (1979A) describes, to

bring together ... information about exposure of members of a population to an agent, with information about the occurrence of a disease in that population, even when such events are separated by substantial distances in time and space. (emphasis in original)

Newcombe (1979) attributes the coining of the term "record linkage" to Dr. Halbert L. Dunn, chief, U.S. National Office of



Vital Statistics, in 1946 when speaking to a group of Canadian vital statisticians. Martha Smith (1980) credits Dr. H.B. Newcombe<sup>1</sup> with the development and application in Canada of computer techniques for record linkage between the years 1957-1979; this work has subsequently been pursued by Statistics Canada.

Newcombe (1979) states that the earliest studies in Canada were carried out using vital statistics data, showing the feasibility of computer-aided linkage. He then states that when universal hospital insurance and universal medical care insurance came into effect, it became possible in principle to link illness information using similar computer-aided linkage techniques. This he describes as presenting more practical problems than vital statistics linkage. Linking to employment in occupations Newcombe (1979) describes as involving "still greater difficulties".

By definition, record linkage requires individual identifying information for both starting-point (exposure) files and end-point (outcome) files. Personal privacy can be maintained by reporting only grouped data, but individual identifying information is required initially.

---

<sup>1</sup> She cites: Newcombe et al., "Automatic Linkage of Vital and Health Records", *Science*, 130, 954-9, 1959; Kennedy et al., Computer Records for Family Linkage of Vital and Health Records. Chalk River: Atomic Energy of Canada Ltd., 1965; Newcombe, H.B. "Record Linking: The Design of Efficient Systems for Linking Records into Individual and Family Histories", *Amer. J. of Human Genetics*, 19, 335-9, 1967; Smith, M.E. and H.B. Newcombe. "Methods for Computer Linking of Hospital Admission-Separation Records into Cumulative Health Histories", *Methods of Information in Medicine*, 14, 118-25, 1975.

Acheson (1979B) describes the adoption in Great Britain of the techniques of record linkage developed by Newcombe. They were used initially in the 1960's to link vital statistics and hospital administration data into personal cumulative and family files. In England, the National Cancer Register files have been subsequently added to the data base. Scotland has a national record linkage system also, involving hospital discharge records, death records, cancer registration records, handicapped childrens' registers and records from school health exams. These are not held in a comprehensive manner but are linked as required.

In Canada, Statistics Canada has organized mortality and cancer incidence records for access on a national scale (Smith, 1981). Though vital events registration is a provincial responsibility, the Statistics Act of 1918 and Order in Council of 1919 established mechanisms for the uniform registration of vital events, the transmission of copies of these records to Statistics Canada and the publication of vital statistics starting in 1921 (Rowebottom, 1979). Coded cause of death files are machine readable back to 1950 (Smith, 1980).

The National Cancer Incidence Reporting System has been compiling reports from provincial registries (except Ontario) since 1969. Provincial sources of information vary but may include cancer clinic records, general hospital records, cancer notifications from individual doctors, notations of cancer on hospital admission/separation health insurance forms, medicare claims, radiology, hematology or cytology reports (Smith, 1980).

Ontario has recently begun to supply cancer incidence information.

Smith (1981) notes that Statistics Canada has placed an emphasis on the organization of these "outcome" files, since the legislation surrounding the use of statistics in Canada (Statistics Act) limits such a co-ordinating role to the national body.

These outcome data are matched to exposure records relating to a specific interest group (e.g. an occupational group). A fairly sophisticated record linkage system is required since Canadians do not have unique lifetime identifiers, and therefore the record linkage system utilizes a number of identifying items (e.g. name, sex, birthdate, birthplace, parents' names, etc. See also Table I) common to various record sets to determine whether or not they refer to the same individual. Tests of this computer linkage program using ill-health records and birth registrations have demonstrated it to be more successful than manual linking in accurately matching records (98.3 versus 96.7 per cent in one study), with fewer false linkages (0.1 versus 2.3 per cent) (Smith, 1981). Human errors result mainly from incomplete searching, errors in copying and inadequacy of identifying information. Computer errors result "almost entirely" from insufficient or discrepant identifying information, and generally result in failure to find a correct linkage rather than generating a false linkage (Smith, 1980).

Costs of a search are in the area of one to two dollars per record in the cohort, with larger cohorts resulting in lower

cost per record (Smith, 1981).

Studies using these facilities have been undertaken to evaluate long-term consequences of occupational exposures, medical treatments and diagnostic procedures and other circumstances (nutrition, age at first birth). Occupational studies include uranium miners, nickel workers, hard rock miners, radiation workers, as well as workers exposed to asbestos, fibreglass, vinyl chloride and formaldehyde vapour (Smith, 1981).

Accurate linkage of exposure records to outcome records is enhanced by provision of thorough information in the exposure records. Smith's recommended list of optimal personal identifying information appears in Table 1 (Smith, 1981). Smith (1981) recommends that this information be collected from 'employees after hire' as a routine personnel practice; updated information on marital status, place of residence, as well as termination dates, date and place of death if occurred and known, should be added as they occur. In addition, work and exposure histories should be maintained (e.g. jobs held, nature and measure of exposure to potential hazard present). Elsewhere, Smith recommends inclusion of ethnic origin in exposure records (Smith, 1980). It is interesting to note that

---

<sup>1</sup> Since it is a violation of provincial and federal Human Rights legislation to use some kinds of personal identifying information in employment decisions (e.g. place of birth, age, sex, marital status, race, religion) the employer is both being lawful (non-discriminatory) and is seen to be lawful by simply not obtaining personal information irrelevant to the employment decision (that is, not specifically related to ability to perform the job) until after the individual is hired.

the social insurance number (SIN) and health insurance number are not used in the mortality record search, since they do not appear on death certificates. However, they are useful if other identifying items are limited, particularly since social insurance files can be accessed for birth date, first and second given name, and mother's maiden name (for males and single females) or own maiden name (for all married females, including separated, divorced and widowed). Access to these files requires the collaboration however of the Canada Employment and Immigration Commission (CEIC) (Smith, 1980). In addition, inclusion of social insurance number in the exposure record permits fairly simple removal of duplicate entries in the exposure record as well as permits, again with the collaboration of CEIC, the compilation of work histories involving more than one employer.

Statistics Canada protects the confidentiality of individuals' records by releasing statistical information resulting from record linkage only in formats which do not permit identification of individuals (for a further discussion of confidentiality, see chapter III).

These criteria for exposure records will now be used to assess, in a case study model, the adequacy of records on employees/members between 1940 and the present held by a group of employers and a trade union.

Table I - List of Items to be Included in an Employee Health-identifying Questionnaire

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. Mother's maiden surname
15. Mother's first given name
16. Mother's second given name
17. Mother's birth province or country
18. Marital status
19. Spouse's birth surname
20. Spouse's first given name
21. Spouse's second given name
22. Spouse's birth province or country
23. Social Insurance Number
24. Health Insurance Number
25. Pension plan number
26. Current complete address including postal code

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Year	Month	Day

This form is designed to be filled out when the employee is hired. Other information relating to work histories, exposure histories, and updates should be added later. A control code to indicate the work site, a control code digit to indicate alternative entries for the same event (e.g., cases where an individual may have an alternate spelling for surname), and a unique employee number are optional additional items. Termination dates and address changes should be added. A "last known alive date" is of value to reduce the amount of searching required in the death file. If the employee dies, the date of death and province or country of death should be added to the nominal roll file.

From Smith, 1981.

Reprinted with permission of the author.

## II. NOMINAL ROLL DATA BASE CASE STUDY

### A. INTRODUCTION

The practicality of epidemiological research has been aided significantly by the development of microelectronic technology. Locating and matching any large number of outcome records (e.g. death registrations) with exposure records, at one time unthinkable for the amount of human clerical labour it would require, is now possible, cheap and accurate. However, the effectiveness of this work depends to a large extent on the "quality, quantity and discriminating power of items of personal identifying information present on the exposure file that overlap with those available in the [outcome] file." (Smith, 1982).

Statistics Canada has been involved in the organization of 'outcome' i.e. mortality data base files and National Cancer Incidence Reporting System files for the Canadian population; exposure files are assembled by outside organizations which are submitted and linked to outcome files.

What quality of exposure records can be expected in industry? This chapter will report as a case study the status of employment records held by major employers in the coastal lumber industry in the period 1940-81 in an attempt to throw some light on this question.

## B. THE CASE STUDY AS A RESEARCH METHOD

The case study is the most humble of research methods. It is undertaken as an initial, exploratory step in what will sometimes be a more extended research process (Sellitz, et al., 1976; Verhanick and Seaman, 1978). The case study as a research method is generally discussed in the context of formulative or exploratory research whose functions can include clarifying concepts, increasing the investigators' familiarity with the phenomenon in question and gathering information about the practical possibilities for carrying out research in real life settings (Sellitz et al., 1976).

This case study involved at least those functions. It was carried out to assist in evaluating the possibilities and practicalities of continued research on the chlorophenate problem in this industry. It also had the function of familiarizing the investigators with the issues and problems of quality of and access to records in this industry as a possible sample of the situation in similarly organized industries in the province.

The major strength and weakness of the case study approach are both related to the small sample size. When studying only one industry, fairly in-depth information can be obtained, and examined in their natural setting. Visits can be made to actual worksites and offices, individuals who maintain the records systems, perhaps for as long as 20-40 years, can be interviewed, and the actual quality of cataloguing and storage can be assessed. This level of detail may have practical implications



for the quality and cost of any future activities which will have to obtain and use those records. Reciprocally, the major weakness in the case study is the lack of generalizability of the findings of a sample of one. There is no basis on which to say the B.C. coastal lumber industry is typical of B.C. employers and unions in general, or even primary and secondary industry in general. The investigators and the reader are left to assess the usefulness of the description of records in this industry for anticipating the quality and accessibility of records in other places of employment.

An additional weakness of case studies noted by Hillway (1956) is an element of subjectivity. This may be less likely in other more structured designs and of course may influence the validity of results.

Advantages of the case study design in addition to the depth of information usually obtained are the generally low cost, greater ease of getting co-operation due to the informality and flexibility, and the avoidance of artificiality which might result from more structured approaches to the question (e.g. a mail-out survey) (Abdellah and Levine, 1965). With these concerns in mind, the report of the case study can now be presented.

### C. CASE STUDY

In the spring of 1981, the Forest Industry Industrial Health Research Program (FIIRHP) decided to begin the assessment of health impacts of chlorophenates (CPs), chemicals used in the B.C. coastal lumber industry for protection of lumber from sap stain and mould since the late 1930's and 1940's. In 1977 an estimated 55% of the 12.038 billion board feet of lumber produced in B.C. was treated with chlorophenates (Canada, 1981).

A joint union-management committee undertook to explore the health concerns related to exposure to chlorophenates.

Dr. T.W. Anderson, Head of the Department of Health Care and Epidemiology, Faculty of Medicine, UBC, was approached and agreed, with the assistance of the present writer and Dr. Donald Enarson of the Department of Medicine, UBC, and with the support of a research grant from FIIRHP, to determine availability of information on the current and historical working population exposed or potentially exposed to chlorophenates, the quality of information on that population, to review existing literature on CPs, and report on the feasibility of a range of health studies.

The Chlorophenate Feasibility Study, as it came to be known, was supervised by a joint International Woodworkers of America (IWA)-Council of Forest Industries (COFI) committee, whose task was to establish the objectives of the study, facilitate investigators' access to information, assure integration of the work of the CP feasibility study team with the CP health study already underway in Port Alberni (IWA) Local 1-85, and liaise with the FIIRHP steering committee.

The Pulp and Paper Workers of Canada (PPWC) and the Canadian Paperworkers Union (CPU) represent workers at some sawmills on the B.C. coast. Neither of these unions was represented on the FIIRHP committee initiating and supervising the chlorophenate feasibility study for reasons unknown to this writer, but lack of interest or concern is not thought to be one of them. This resulted in no CPU or PPWC offices being visited, nor were mills organized by those unions visited, nor was any information collected from members of those unions. As of January 1, 1982, CPU membership was 7600, PPWC was 7150 and IWA was 42,000 (British Columbia, 1982).

Six of the eight coastal B.C. IWA locals were visited and telephone interviews were conducted with the remaining two. Ten head offices of the sixteen companies involved were visited as well as seven of the thirty-one coastal sawmills operated by those companies. Visits to union locals consisted of interviews regarding the nature of records kept on current and past union members, health concerns related to CPs and identification of worksites represented by the union local known to use CPs in anti-stain treatment. Visits to millsites involved tours of the anti-stain treatment areas with a union and management representative, and interviews with supervisors and administrative staff in personnel, payroll, quality control and/or production regarding the plant history of anti-stain treatment, health concerns, and nature of records on current and past employees. At MacMillan Bloedel sites, a meeting was held with union-management health and safety committees.

The remaining companies and sites were contacted by telephone. This was necessitated because the industry went on strike in mid-July, the contact information for companies other than MacMillan Bloedel was not received until June 15, 1981, and the goal for production of the feasibility study report was mid-August. However, for the most part, the quality of information gathered through telephone interviews was better than might have been expected because of the familiarity with the technological and personnel side of the industry established through the fairly careful site visits in early July and the circulation of the feasibility study summary outline to site managers prior to telephone contact. What was lost was information of union health and safety representatives at sites not visited about health concerns or specific exposure concerns particular to each site.

Current workforce population figures were collected from mill managers, union locals and the Vancouver Forest District, B.C. Ministry of Forests, mill list for 1979.

Historical data for the population of individual mills was difficult to obtain. Company information was usually a rough estimate based on recollection of individual long-service staff. However, the Vancouver Forest District, B.C. Ministry of Forests, maintains a mill list, updated annually, giving employment and production figures for each site; these detailed records were not retained prior to 1976. As a result, best estimates of total mill populations were obtained from Vancouver Forest District annual reports, where total sawmill/planer

employment in the district is reported for most years. These reports show that the total number of workers has ranged from approximately 12,000 to 19,000 each year from 1944 to 1979; in 1979, total workers in the district were given as 18,107.

(Note: the Vancouver Forest District includes all 31 mills identified by company representatives on the FIIRHP committee as relevant i.e. using chlorophenates).

Forest district estimates for 29 of the 31 mills identified account for about 55% of the total district mill employment. Company figures of employment for the 31 sites accounts for about 49% of the total district mill employment figure. Inclusion of the three woodroom populations known to be exposed to CPs would bring the proportion of total workers included to about 60%, i.e. between 7,200 and 11,400.

#### D. RECORDS

##### 1. Union Records

IWA membership records are held at local union offices. Similar records are held in all offices visited. A membership registration card (original sign-up card) shows name, address, initiation date, place of employment and social insurance number (SIN). The dues card holds the same information plus a number showing which card in the series the particular card is. Monthly payments are recorded. Some dues cards identify a death fund beneficiary (at least three locals have a death benefit fund). The only work related information held is place of

employment; no detailed job information is held.

All locals appear to have complete sets of current and terminated members' cards back to 1948 or 1950<sup>1</sup>. Active members are cross-indexed by name and place of employment; inactive members are usually filed alphabetically.

At least three locals have death benefit fund registration cards, but they are generally not retained for terminated members. The only information beyond that held on the dues cards is name and address of the beneficiary. Two locals reported retaining a list of individuals for whom death benefit payouts had been made; one has records only since 1971; the other advised that records prior to 1971 were difficult to access. Cause of death, if known, is not a formal part of the record.

Seniority lists for each operation organized within the local are held for the current year, but availability of historical lists is patchy. Nowhere was it certain that complete sets were retained, although at some locals there are some lists dating back to the 1950's.

A list of people ever working at mills using CPs from union records could be generated, back to 1948 or 1950. Alphabetical files of terminated members would have to be reviewed and individuals recorded who were shown to be employed at relevant mills in relevant years. Duration of employment is retrievable, along with SIN, last known address and any beneficiary

---

<sup>1</sup> All union records prior to this time were destroyed as a result of a change in the political leadership of the union.

information held. Death benefit fund payout data could be retrieved where available and used to compare with pension plan/health and welfare fund payouts where applicable.

## 2. Company Records

There are two major sources of nominal roll information for employees: a) personnel records and b) payroll records.

### a. Personnel Records

Most operations create a manila file and some kind of card record on each employee. A few also create a skills inventory and/or training program record which lists each employee. Personal information is usually recorded in the manilla file and on the card, including name, address, phone, social insurance number. Sometimes held are: date of birth, previous employer, hire date, job(s) held, height and weight, marital status, next of kin, nationality, education, dependents, employee number. Older forms and cards (1940's) tend to hold more personal information than recent ones. Termination date is usually recorded for terminated employees.

Eighteen sites (of 29 interviewed) reported retaining personnel files of terminated employees for at least some period; at least 14 hold complete or nearly complete records. Many have personnel cards for a longer period than files, and at least two have consistently retained cards though not files. Accurate job histories are not always recorded, either by job

transfer notices to file, or entries on the card, nor do personnel staff assure their comprehensiveness where they do exist. However, this is the best source of historical exposure information identified. At least seventeen sites reported job change information is held in personnel files or on card systems.

b. Payroll Records

Payroll records are the most frequently retained records. At least 19 sites have complete or extensive payroll records and at least five others have some historical payroll records.

Recent payroll records are usually computerized and show date, name, pay rate, gross earnings, deductions. Depending on the operation, an employee number, hours worked, occupation code, pay rate, seniority date, address, social insurance number and company division may also appear.

Older records consist of payroll cards, manually maintained, which vary in the amount of information they contain. Many give a job title, pay rate, address, deductions, date.

Some sites have retained only T-4 (federal income tax statement of gross earnings) forms for any years beyond the most recent. These show only name, address and gross earnings.

Generating lists of all people ever employed from payroll records may be fairly easy for the past ten years or so, since most operations are using some kind of computerized records. Prior to that the task becomes increasingly labour-intensive,



requiring in many places manual review of cards which were made up for each employee for every two weeks or month. This amounts to a very large number of cards, most of which will repeat for continuous employees but each of which needs to be reviewed to determine if it is an individual not yet recorded. The task would be an onerous one but not impossible. These records are sometimes filed carefully in labelled filing cabinets or boxes. In other cases they are simply bundled up and stacked in cupboards, attics, basements or outbuildings. In one or two places sections of records have been destroyed accidentally by water or other disasters, and in a few places sections were simply thrown out to make more space.

c. Other Records

The only other sources of nominal roll information are social club or "25 year club" lists and pension lists prior to the 1973 industry-wide plan. The quality of these records appears to be directly related to the quality of historical personnel records, and so did not appear to be a useful alternate source for identification of ever-employed people. However, at specific sites they may assist in checking the reliability of lists generated through review of payroll and/or personnel records. Similarly, workers' compensation claim records and sick leave claim records are most frequently filed in the individual's personnel file, and therefore do not offer an alternate source of nominal roll information. In some companies, these records are filed alphabetically in year and

subject files e.g. Workers' Compensation Claims, 1980. They offer no more personal information than is available from personnel and payroll records, and are by their nature not an exhaustive list of ever employed, so are not of importance in generating nominal roll information.

## E. SECONDARY DATA SOURCES

### 1. IWA/FOREST INDUSTRY PENSION PLAN

The plan holds records of all IWA members employed with participating companies in Western Canada (1200 worksites) since 1973. The plan records show name of enrollee, employer by year, address, birthdate, union local and hours worked. There are approximately 53,000 active woodworkers in the plan in Western Canada, 100,000 names currently in the plan and a total of 200,000 individuals ever in the plan (personal communication: Joan Diaz, pension administrator, IWA regional office, August 1981). Next of kin information is held for people who are over 55 years and have enrolled in a beneficiary option, or are currently receiving a pension. The plan also holds information on place of employment prior to 1973 submitted by companies for individuals employed with them prior to 1973 and still employed in 1973, or submitted by individuals to substantiate pension plan credits. The pension plan makes no claim to comprehensiveness of work records prior to 1973. Job title information is not held in plan records; division where employed

and union local is the smallest breakdown of job related information.

The plan holds a file of people who died while retired (since 1973); it is known as "class 9" and includes 1963 files as of May 31, 1981. Also in this file are people who died while employed if the plan was advised of the death by the company. Deaths may not be completely accurate for three reasons:

i) the pension plan has two computer systems, one which generates cheques and one which maintains records. Mr. Norman, plan administrator, stated (August, 1981) that it is not guaranteed that information to cease payments is also recorded in all instances in the other computer system, i.e. by inclusion of the individual in class 9;

ii) class 9 also includes files of individuals who died while working, and whose employer advised the plan of the death. Some employers may regularly advise the plan of these events, some may never, and some may do so sporadically. These could be identified in a review of the files, but what proportion such deaths are of the total class 9 population is not certain without such a review;

iii) the existing pension plan administration is the result of an amalgamation of two plan administrations in 1978. Whether complete data on deaths had been held previously and fully amalgamated into the joint records is not certain.

## 2. IWA/FOREST INDUSTRY HEALTH AND WELFARE PLAN

This plan has been in effect since October, 1961. Wm. M. Mercer Ltd. have been the administrators since that time, maintaining information on eligible employees. Crown Life was the insurer for all benefits to 1981; they continue to handle the group life insurance benefit. CU&C is, since 1981, the adjudicator of weekly indemnity claims.

Enrollment cards are held on each enrollee. They include name, social insurance number, company, division; no address, phone number or job title are included. Paper records are not retained beyond one and a half year by Wm. M. Mercer. However, enrollment cards are also held on microfiche; these records are comprehensive back to the early years of the plan.

Life insurance death benefits are payable for death while working, accidental death on and off the job, death while on sick leave or Workers' Compensation, or for people who are disabled but no longer on sick leave or compensation but still are enrolled in the group life plan. Not included are pensioners.

Mr. Reid of Wm. M. Mercer Ltd. advised (August, 1981, personal communication) that data from the Health and Welfare Plan are accessible for the past five years, feasible to access for the past ten years and somewhat more difficult beyond ten years. Problems in access are due to administrative problems with the plan in the early years and the fact that Mercer's offices have moved twice since 1961; Crown Life's offices have moved three times in the same period.

These data bases are the most centralized source of nominal roll information potentially going back to the early 1960's. Personal identifying information in these records is limited however and might need to be supplemented by personnel and payroll records.

#### F. EXPOSURE HISTORIES

Ideally, exposure information would be of two kinds:

- i) industrial hygiene data quantifying kinds of temperature, noise, vibration and chemical exposures throughout the production process, along with details of which jobs are subject to which exposures, and
- ii) comprehensive individual work and exposure histories, documenting location and duration of jobs performed as well as any individual measurements done, whether audiometric, blood, urine, lung function or other physical evaluation (e.g. weight over time, reporting of other health problems such as dermatitis, nausea, headaches, etc.).

Existing data in this industry were limited. Union records show only initiation date and place of employment; no other job information is held. Company records are somewhat more helpful in this regard. Recent years have seen the development of skill inventories and/or training program records which track employees through job changes. These are not commonly held and are fairly recent, and therefore are of limited usefulness in the short term.

Personnel files sometimes enter job changes either by notification slips from supervisors or entries on a personnel card. This is not done in all companies nor do personnel staff assure that such a record is complete and accurate even where it is done. To the extent that it does exist, it is the best source of historical information available. Seventeen of the thirty-one sites investigated reported such job information is held by the personnel office.

Operations usually have a daily "personnel report" or "manning sheet"; it is a daily record of who worked in which positions, filled out by supervisors on each shift. This record is potentially very valuable but nowhere was it reported to be retained beyond two to three years.

Payroll records do not usually indicate a job title, but rate is either shown or determinable from a calculation of hours worked and gross earnings. At least one pay office reported holding historical wage lists all the way back to 1933. Currently there are twenty-three different pay rates for jobs within the bargaining unit in sawmills and planer mills; various people in the industry reported that historically there were many more rate differentials. This suggests that where no specific job information was obtainable for an individual on the nominal roll, some assessment of exposure could be made by determining a likely job held as indicated by wage information from payroll records checked against an appropriate wage schedule.

T-4 forms, the most widely held pay record for early years,

are of little assistance in determining exposure information.

Records of individual medical or health status are limited. Only one operation reported conducting pre-employment medical exams; one other reported ceasing this practice in 1975. All others advised such exams had not been done and all operations stated no in-service medical exams were or are conducted. The pre-employment medicals were described where practiced as screening for physical fitness to do manual labour. Other companies stated such screening was done through application form questions inquiring whether the individual had any health problems restricting their ability to do the job applied for. Changes in health status (e.g. weight loss) are, as a result, not generally available.

The only in-service medical or health records reported were first aid records and WCB audiometric test results. Both union and management representatives advised that complaints of problems now recognized as potentially linked to CP exposure (respiratory problems, skin problems, nausea) are of a nature not typically reported to first-aid attendants, although reporting of problems identified with CP exposure has increased in recent years.

The only other source of medical or health information reported was Workers' Compensation claim forms and sick leave claims under the Health and Welfare indemnity plan. These are frequently filed in an individual's personnel file; in some operations by year and alphabetically in a subject file e.g. WCB claims, 1980. Few WCB claims are filed that report CP

exposure as a causative factor; of approximately 350 dermatitis time loss claims allowed per year with the B.C. Workers' Compensation Board, only six in 1980 were identified as associated with CP exposure (personal communication, WCB representative, August 1981). Thus it appears on the basis of current information that WCB claims or Health and Welfare plan claims could provide little assistance in identifying job/exposure relationships in this industry.

#### G. GOODNESS OF FIT

Table II shows which of the personal identifying information preferred by the Statistics Canada record linkage program is obtainable from each of the sources mentioned above as well as the B.C. death certificate. Obviously, information is patchier than is most desirable.

Mechanisms are available which could improve upon the amount of information held on each individual. For example, nominal roll lists could be submitted to local committees of high seniority union and management people requesting additional information. This practice might be most useful in establishing exposure histories and groupings and last known alive date.

Recovery of as much personal identifying information as possible for all those ever employed since 1940 in coastal lumber mills using CPs would involve reviewing a variety of source documents, most of which are only easily retrievable by computer technology in recent years.



Table II - B.C. Coast Lumber Industry: Identifying Information Available

	<u>Records:</u>			Joint Pension	Joint H.&W. Plan	B.C. Death Certificate
	Union	Personnel	Payroll			
Surname	+	+	+	+	+	+
Previous surname	-	(+)	-	-	-	+
1st given name	+	+	+	+	+	+
Other given names	(+)	(+)	(+)	(+)	(+)	+
"Usual" name	(+)	(+)	(-)	(-)	(-)	-
Sex	+	+	+	?	?	+
Birthdate	-	(+)	(+)	+	?	+
Birthplace	-	(+)	-	-	-	+
Father/Mother names & birthplaces	-	recent - older (+)	-	-	-	+
Marital status	(+)*	(+)	(+)	(+)	(+)	+
Spouse's name/ birthplace	(+)*	(+)	-	(+)	(+)	+
S.I.N.	+	+	(+)	-	(+)	-
Health Ins. Number	-	-	-	-	(+)	-
Can. Pension Plan Number	-	-	(+)	-	-	-
Current Address (while a member/employed) +		+	(+)	+	-	+
Hire/ Term. date	+	+	+	+	+	-
Occupation	(-)**	+	+	-	-	(+)**
Place of death	(-)	(-)	-	(+)	(-)	+

Symbols: + : available in record      (+) : possibly available in record  
 - : not available in record      (-) : small possibility of availability in record  
 ? : no known if information held.

\* - this information may be known if a death benefit fund exists and the spouse is the designated beneficiary.

\*\* - place of employment will be known; position held, other than bargaining unit member, will not be known.

\*\*\* - recorded as "kind of work done during most of life", and "kind of business or industry in which worked".

For the feasibility study, it was estimated that seventy-five per cent of the records on all those ever employed since 1940 are paper records. An estimate of thirteen person-years of clerical work was proposed to examine pay records for three monthly intervals back to 1940. Staffing costs for this task were estimated at \$260,000. Validation (or supplementation) through examination of union records was estimated to cost an additional \$130,000. Additional costs would be incurred by attempting to integrate health and welfare plan, pension plan, or management, co-worker, or personal recollection into the data base. The attraction of using all available sources to maximize personal identifying information is that this would lower costs and increase the efficiency of the record linkage with outcome registries.

### III. POLICY ISSUES AND OPTIONS

#### A. IMPROVING THE FIT: POSSIBLE MECHANISMS

Given a recognition of the inadequacies of current patterns of record keeping for occupational health research, as suggested by the case study, and a desire to improve the data base, identification of actors in the field of occupational health and safety and potential mechanisms for altering the current circumstances is in order.

In a report for the Economic Council of Canada, Hushion, Olgilvie Associates Ltd (1981) identify participants or "stakeholders" in occupational health and safety decision-making processes. They list:

- provincial government bodies including the cabinet and cabinet committees, the caucus of the governing party, relevant executive arms of the government, departmental staff, opposition parties and their research organizations, Royal Commissions and other public policy review bodies;
- labour organizations, including union locals, national or international bodies, union research staff, provincial and national federations;
- employer organizations, including provincial and national organizations and organizations representing industrial sectors;
- occupational health and safety agencies, public

interest groups, and associations including technical expert groups, (e.g. Canadian Centre for Occupational Health and Safety, Canadian Standards Association, Canadian Medical Association, Canadian Public Health Association, Windsor Occupational Safety and Health group (WOSH), Vancouver Committee on Occupational Safety and Health (VanCOSH);

- individual professionals and experts in the field (e.g. at universities or employed by individual firms or unions);
- other government bodies, including other departments within a province and other provincial and federal agencies with similar responsibilities;
- and finally individual employers, unions, occupational groups or individual workers.

Some of these can be eliminated as decision-takers i.e. able to take action which would improve the data base for research. For the most part, only large employers and employer associations who anticipate being in operation twenty to fifty years in the future are likely to invest in improved record keeping for the purpose of occupational health and safety research. For most employers the investment in record keeping for research purposes cannot be economically justified. The economic rationale for this non-investment was briefly referred to in chapter 1 and is more fully described in Appendix A.

Technical expert groups and individuals, as well as interest groups not composed of employers or trade unions have

no authority to take action with respect to record keeping, so can also be eliminated as actors in this area.

Governments other than provincial authorities in the jurisdiction in question are in the same position as interest groups. This leaves provincial and federal governments and their staff responsible for health and safety regulation in their respective labour jurisdictions <sup>1</sup> and trade unions as actors who have potentially an interest and ability to improve the quality of exposure records available for occupational health research.

What mechanisms are conceivable to affect the maintenance of record systems? Three routes can be identified:

- i) federal and provincial labour legislation,
- ii) statutes or regulations of agencies responsible for occupational health and safety;
- iii) terms negotiated in collective agreements.

---

<sup>1</sup> Federal jurisdiction includes railways, longshoring, interprovincial highway transport, shipping and ferries, telecommunications, air transport, post office, banking, grain elevators and the federal public service. Federal Department of Labour employees are responsible for safety inspection and accident prevention under parts three and four of the Canada Labour Code. Provincial jurisdiction includes all other places of employment (Steeves, 1982).

## 1. Federal And Provincial Labour Legislation

Relevant legislation includes such employment-related areas as the Canada Labour Code, the Canada Pension Plan, the Unemployment Insurance Act, provincial pension acts, provincial employment standards acts (in B.C., The Employment Standards Act), labour relations legislation (in B.C., the B.C. Labour Code), and workers' compensation legislation. All of these pieces of legislation variously require that records be kept, and often be available on request for inspection or audit by authorized people (Anson-Cartwright and Hollingshead, 1980). The period for which such records are required to be kept by statute are often not specified (Anson-Cartwright and Hollingshead, 1980), a situation which has given rise to criticism of government (Coffman, 1979). Organizations such as ARMA (Association of Records Managers and Administrators) have been urging the reform of regulations dealing with records retention. The major motivator in urging such reform is concern about the costs of maintaining records indefinitely.

Currently in Canada the following kinds of personnel records are required by statute to be retained (summarized from Anson-Cartwright and Hollingshead, 1980):

- Canada Pension Plan: requires annual payroll register detailing employee contributions to be kept until written permission is sought and received to destroy.
- Pension Benefits Standards Act (federal) and some provincial Pension Benefits Acts: require pension

plan payroll registers, actuary reports, contribution records, etc. to be retained. Federal legislation specifies five years; provincial legislation generally does not specify retention time period.

- Unemployment Insurance Act: requires payroll register detailing employee contributions and employee social insurance numbers to be retained until written permission is received to destroy them.
- Canada Labour Code: requires employee files including applications and transfers, job descriptions, payroll registers detailing hours worked and wage rate, time cards, union contracts, and labour relations records and correspondence to be retained for three years from the time the work is performed.
- Canada Labour Code requires records of accidents and injuries to be retained for one year.
- Provincial labour standards legislation requires employee files including (usually) hours worked and wage rates, payroll registers, and record of vacations to be retained. The time period varies from none specified in some jurisdictions to a few months to up to five years following termination in other jurisdictions.
- Provincial workers' compensation legislation

requires retention of payroll registers and records of injuries and first aid treatment for unspecified periods of time.

These records are only a small fraction of the records business is required to retain. Legislation on income tax (federal and provincial), sales tax (federal and provincial), custom duties, incorporation and liquidation, all require record retention. The (now defunct) Office for the Reduction of Paperburden (Federal Department of Industry, Trade and Commerce) submitted to the federal government a proposal to clarify what records must be retained and for what periods of time. Government watchers suggest these recommendations have a good likelihood of being implemented (Lamphier, 1982). Taxation records (which potentially will cover a good portion of nominal roll information) are recommended for a six year retention period, according to Lamphier (1982).

Provincial and federal legislation does not impinge significantly upon the record keeping patterns of labour organizations. Nancy Stinson (1977) states

... unlike business,...Canadian labour organizations are under little statutory compulsion to keep certain types of records.... Labour organizations make no profits, and therefore do not pay taxes and cannot receive tax credits. Money put into record keeping brings no direct or indirect tax deductions. ... The result is predictable: with few exceptions, union records are poorly organized and serviced... disposal is haphazard.



The above discussion suggests that, particularly with respect to business, there are well-established mechanisms for requiring the retention of records. There are real questions however about the effectiveness of these rules, particularly beyond periods of five years, given the myriad of overlapping jurisdictions and purposes, and the apparent resulting confusion and irritation in the business community. Costs of retaining records beyond ten or even five years may be increasingly protested, unless incentives such as tax credits can be provided.

## 2. Occupational Health And Safety Regulations

The Workers' Compensation Board of B.C. is constituted under the authority of the Workers' Compensation Act. It has responsibility for compensation for injury or death arising out of and in the course of employment (section 6(1)), compensation for industrial disease if the worker is disabled from earning full wages or dies of the disease (section 7(1)), and responsibility for making regulations, of general or special application, applying to workers, employers, and all other persons working in or contributing to the production of any industry within the jurisdiction of the Act, "for the prevention of injuries and industrial diseases in employments and places of employments" (section 60(1)). The Act states specifically that "The Board may issue orders and directives specifying the means or requirements to be adopted in any or all employments or places of employment for the prevention of injuries and

industrial diseases" (section 60(2)). The Board is specifically authorized to inspect places of employment, engage in educational programs, and undertake or support research.

B.C. is the only jurisdiction in Canada where the compensation and prevention services are carried out by the same agency, external to the provincial government. This has been the case since the Board was established in 1917.<sup>1</sup> This joint responsibility, although unusual, was specifically recommended by the Pineo Commission in 1916 in the hope that awareness of the hazards of employment as evidenced by compensation claims would provide motivation for effective preventive action (Reasons, et al., 1981).

The territory covered by industrial health and safety regulations (previously known as accident prevention regulations) in B.C. is broad, ranging from specific physical arrangements to permissible levels of toxic substances, to practices and procedures to be adhered to, to constitution of

---

<sup>1</sup> The B.C. Ministry of Labour retains some jurisdiction over occupational environments via, for instance, the Factories Act. This involves standards for heat, light, ventilation and sanitation in most workplaces as well as the labelling and disposal of dangerous substances. Also, the authority to inspect mines and train mining blasters is retained by the provincial government under the Mines Regulations Act, administered by the Ministry of Mines and Petroleum Resources. Agricultural workers are not included in any compensation or occupational health and safety program until April 1983, when they will be under the jurisdiction of the Workers' Compensation Board. Domestic workers continue to be excluded from any such program. Areas of employment under federal jurisdiction (the Canada Labour Code) are inspected by the provincial agency for occupational health and safety issues under a cooperative arrangement. Note also that the Commissioners of the B.C. Compensation Board are appointed by the Lieutenant-Governor in Council (essentially the provincial cabinet) (Steeves, 1982).

programs and committees at workplaces. With respect to record keeping, a number of regulations already exist requiring employers to maintain particular records on employees.

The most general, and for the purposes of this discussion, the potentially most useful, is regulation 4.5(f). This regulation stipulates that the contents of an industrial health and safety program, which is required in all workplaces depending on the number of employees and hazard category, or at the direction of a Board officer, include "the maintenance of records and statistics, including reports of inspections and accident investigations,...".

Additional and more particular references to maintenance of records on employees are as follows:

- section 13.35(5) provides that employers shall maintain permanent records for each worker in an audiometric program and that the record will be kept for at least five years after termination of employment.
- section 78.11 provides that medical records generated under the requirements for particular occupations "shall be maintained under the custody and control of the occupational physician in a manner acceptable to the Board" and that it is not available to the employer or any person other than the Board without the informed consent of the worker. Note that section 78, dealing with occupational medical concerns, has not yet been

declared to be in effect.

- Records are also required to be kept and made available for various pieces of equipment and atmospheric testing (sections 40, 56 and 72).

These regulations certainly establish a precedent for the Workers' Compensation Board to require that records be kept by employers. A mechanism exists then for the Board in B.C. to require employment records of a specified nature (e.g. containing information proposed by Statistics Canada as optimal for linkage purposes) to be held in a similar manner with respect to confidentiality as the medical records described in section 78.11 of the existing regulations. This could be done within the joint mandate of preventing injuries and disease and investigating accidents and causes of industrial disease, as described in the B.C. Industrial Health and Safety Regulations, 1978, page viii.

The mechanisms described for B.C. could be applied in any of the other jurisdictions in Canada. Occupational health and safety agencies exist in all provinces and regulations across jurisdictions are substantially similar. This results from the regulation and inspection orientation which developed historically in North America as a whole with respect to occupational health and safety programs. Trends in the 1970's in Canada have continued in this approach, with the enactment of comprehensive health and safety legislation in a number of jurisdictions and the administrative consolidation of various

government programs (Aykroyd, 1978). Some emphasis on record keeping can be seen in recent legislative changes; for instance, the Ontario Health and Safety Act of 1979 requires employers to maintain records on individual worker's exposure to particular industrial agents.

### 3. Collective Agreements

Collective agreements in B.C. reflect limited activity in negotiations on health and safety issues. Twenty-eight per cent of contracts reviewed by the B.C. Ministry of Labour in 1981 had no provisions dealing with occupational health and safety (note: contracts reviewed were those covering more than 100 workers and submitted to the Ministry; 379 contracts covering 330,425 workers were reviewed) (Negotiated Working Conditions 1981, B.C. Ministry of Labour).

Variation across sectors is significant. Construction contracts most frequently have occupational health and safety clauses of some kind; only 3/37 contracts in this area have no provisions, affecting only six per cent of the workers represented by those contracts. Trade and service sector contracts are least likely to have occupational health and safety provisions: 22/35 contracts have no provisions, affecting 72.7% of the workers represented. Health, education and crown corporation contracts come close behind, with 38/82 contracts have no provisions, affecting 60.3% of the workers represented.

Where occupational health and safety appears in contracts,

it for the most part is to provide for joint health and safety committees (which are mandatory in B.C. in a number of sectors where more than 20, or in some cases 50, workers are employed), establish rules about clothing and equipment, and address refusal to work in dangerous conditions (again, rights provided through health and safety regulations of the Workers' Compensation Act). Where legislated rights and responsibilities are written into collective agreements, they do not reflect gains due to collective bargaining, but may reflect an interest by either or both parties to educate themselves and remain alert to these issues.

The remaining area addressed by relevant provisions is pay for health and safety committee members for time spent on committee matters. Twenty-three per cent of agreements in manufacturing (covering 57% of workers), 10.8% of agreements in construction (11.5% of workers), 41.35% of agreements in other industries (33.6% of workers), 15.9% of agreements in health, education and crown corporations (9% of workers) and 2.9% of agreements in trade and service (0.8% of workers) provide for pay for time spent on safety and health committee matters.

Notwithstanding the limited nature of provisions currently in collective agreements regarding occupational health and safety, as demonstrated by the summary above, it is quite possible to conceive of contract language that would address the issue of adequate nominal roll information to be held in perpetuity. Such a clause could specify exactly what information would be collected, presumably post-hire; whether or

not it would be held independently of personnel and/or payroll records; what information would not be held; whether or not duplicate files would be held by the employer and the union, or by only one of them and which one, or by a third party; and what conditions might be attached to use of such records. This last category might be as broad as providing simply that any use must be jointly agreed to by both parties or might specify a committee or individuals who have the responsibility of approving use and access, or even specify the kinds of purposes to which the data can be made available and purposes for which it is not to be released.

An existing situation which has some of these characteristics is the joint IWA/Forest Industry Pension Plan. The Plan has a board of directors composed of both employer and IWA representatives. Access to the pension records held for purposes of occupational health research requires the approval of the board (presumably for parties other than the plan administrator).

#### 4. Conclusion

A number of mechanisms have been identified for improving the quality of nominal roll information for use in occupational health research. The final section of this chapter will discuss these again briefly in the context of realistic policy options.

## B. THE CONFIDENTIALITY ISSUE

Any discussion of research is not complete without attending to the ethical questions surrounding the sources of data, its use and dissemination. A number of important social issues are involved, specifically those of privacy, confidentiality, and the individual's access to his/her own records, as well as the desire for increased access by researchers for use of personnel records in the public interest. This section will attempt to provide useful definitions of these concepts, an evaluation of the significance of microelectronic technology, and a review of some proposals that have been made to resolve the apparent conflicts in this area.

### 1. Privacy And Confidentiality As An Issue

The question of the individual's right to privacy versus the potential interest and ability of governments and their agencies, employers, medical care providers and institutions, police and the justice system, financial institutions and marketing organizations, among others, to obtain, use and disseminate personal information has become a topic of international attention. Some of the major studies in the area are the following:

- Report of the Committee on Privacy (the Younger Report), Great Britain, 1972;
- Data and Privacy, Report of the Committee on



Automated Personal Systems, Sweden, 1972;<sup>1</sup>

- Privacy and Computers, Canadian Departments of Communications and Justice, 1972;<sup>1</sup>
- Records, Computers and the Rights of Citizens: Report of the Secretary's Advisory Committee on Automated Personal Data Systems, U.S. Department of Health, Education and Welfare, 1973;
- Commission on Automation and Liberty (Commission Informatique et Libertes), France, 1975;<sup>2</sup>
- Personal Privacy in an Information Society, Report of the Privacy Protection Study Commission, U.S. Congress, 1977;
- Privacy and Personal Information, Australian Law Reform Commission, 1980;<sup>3</sup>
- Report of the Commission of Inquiry into the Confidentiality of Health Information (the Krever Commission), Ontario, 1980.

Not surprisingly these studies have generated legislative action on the one hand (e.g. the U.S. Privacy Act of 1974 affecting access to U.S. federal records for research purposes, among other things; the U.S. Tax Reform Bill of 1976 forbidding release of any information from tax returns), and conferences,

---

<sup>1</sup> cited in U.S. Department of Health, Education and Welfare, 1973.

<sup>1</sup> cited in U.S. Department of Health, Education and Welfare, 1973.

<sup>2</sup> cited in Westin, 1976 and Krever, 1980.

<sup>3</sup> cited in Krever, 1980.

position papers, journal articles and general discussion at various levels and among various professional and policy making bodies on the other.<sup>1</sup>

This wave of concern has created such a stir as to warrant, according to some authors, a description as a 'revolution'. Reinert (1981) states "during the last fifteen years privacy concerns have become acute, provoking a social response that has been termed 'a privacy revolution'."<sup>2</sup> Causes of this heightened public concern are attributed by Reinert (1981) to increasing public distrust of social institutions and the perceived ability of new electronic data processing technology to increase the power of institutions in collecting, maintaining, using and disseminating personal information. Westin (1976) similarly attributes increased concern to distrust of government which, speaking about the USA, he dates from the late 1960's and particularly the Watergate revelations of 1973-4. This climate of distrust is in contrast, Westin argues, to the period 1932-68 which saw growing public acceptance of government authority revealed in the 'New Deal' of the 1930's, the U.S. role in World War II and the Cold War, and the Great Society programs of the 1960's. Westin also credits increased concern about medical

---

<sup>1</sup> For example: B.C. Health Association, Discussion Paper on the Confidentiality of Health Information, July, 1982; National Cancer Institute Workshop on Computerized Record Linkage in Cancer Epidemiology, Ottawa, 1979; Hazards at Work: Law and the Workplace, National Seminar, Toronto, 1977; Medical Research Council of Canada, Working Group on Ethics in Human Experimentation, 1978; plus see a number of journal articles referenced in the bibliography.

<sup>2</sup> Reinert (1981) cites Miller, "The Privacy Revolution: A Report from the Barricades", Washburn Law Review, 19(1), 1979.

records and information specifically to the entry of consumerism and a civil rights (patients' rights) stance into the health care field in the last fifteen years.

The discussion of civil rights and human rights concerns generally in the last twenty-five years has had at its centre the dignity of all persons, regardless of race, or sex, or age, or ability, or social class. Krever(1980) makes the link between this concept and the privacy/confidentiality issue in his opening comments in the report of the Ontario Commission:

The need for privacy that all of us have ... [ is ] a dimension of human personality and dignity ... ( v.1 p. 6). ... Confidentiality is fundamental ... to the preservation of the dignity and integrity of the individual ... (v.3 p.41).

## 2. Some Definitions

A frequently quoted definition of privacy, and the one adopted by the Krever Commission (1980) is from Westin (1967):

Privacy is the claim of individuals, groups and institutions to determine for themselves when, how, and to what extent information about them is communicated.

Reinert (1981) makes the point that

central to the many definitions of privacy that have been proffered is the preservation of individual autonomy and dignity against the intruding and conforming pressure of social organization.

A definition of individual privacy based in individual control over personal information is the starting point for most recent examinations of privacy and record keeping.

The concept of confidentiality shifts attention slightly to focus on the role of individuals and institutions who hold or have access to personal information about other people. Confidentiality speaks to the responsibility to hold in confidence that which is private, meaning of a personal nature. Krever(1980) states:

Implicit in the definition [of privacy] is the existence of an obligation on the part of those in possession of the information to respect the claim [to determine when, how, and to what extent personal information is communicated to others] of those whom the information concerns.

Westin (1979) provides practical definitions of these two concepts which he states were also used in the U.S. Department of Commerce, National Bureau of Standards study (Westin, 1976) and a National Academy of Sciences' Project on Databanks (1972).<sup>1</sup>

- Privacy : the question of what personal information it is relevant for an organization to collect or store at all.
- Confidentiality : the question of how information about individuals should be distributed within the organization and when it should be released to outsiders.

---

<sup>1</sup> Westin, A.F. and M.A. Baker. Databanks in a Free Society, New York, Quadrangle , 1972 cited in Westin, 1979.

### 3. Individual Versus Public Interests

Much of the evidence and opinion presented to the Krever Commission (1980) by researchers had as its purpose to establish that there is a public interest served by research which accesses personal information. Examples of evidence making this argument were quoted at length in the Krever Commission Report (1980), including the presentation of the Faculty of Health Sciences, McMaster University, journal articles by Sir Richard Doll <sup>1</sup> and Leon Gordis and Ellen Gold (1980). Gordis and Gold (1980), as well as offering specific examples of studies using records that have made significant contributions to human knowledge of disease causation, present a clear statement on the issue of private versus public interests in the area:

Society has a vital stake in epidemiological and other medical research. We must ensure that the dignity and privacy of subjects will be protected without hindering the advancement of knowledge of disease. The social contract that facilitates the existence of individuals within social groups requires that each individual occasionally yield some of his rights, including privacy and freedom of action, for the benefit of society as a whole. ... Each society must decide when a limited compromise of individual rights is justified by the potential benefits to be derived by the community as a whole. Investigation of the etiology of disease and natural history of disease and of the effectiveness of preventive and therapeutic interventions are of great potential benefit to society, but the conduct of such studies requires that, with proper safeguards, individually identifiable data from medical records continue to be made accessible for medical and epidemiological research.

---

<sup>1</sup> Doll, R. "The Epidemic of Cancer", Cancer, 45, 2475-85, May 15, 1980 cited in Krever, 1980.

Krever found the evidence compelling and agreed that the individual's right to confidentiality is not an absolute one, but a limited right. "Despite my strong conviction that confidentiality is fundamental, ..., I am persuaded that research is one respect in which the benefit to society by researchers' access to personal health information outweighs the possible risk to the individual." (Krever, 1980. v.III)

Judgement must be relied upon in each case however: "the determination must still be made of the circumstances in which the balance favors society." (Krever, 1980. v.III)

This determination that individual interests must be weighed against public interests echoes an earlier statement by Howard B. Newcombe, a Canadian active in the field of record linkage and epidemiological research. In a speech at a national seminar titled Hazards at Work held in Toronto, Ontario in 1977 he described the issue this way:

What are the rights of the people involved? I would propose that there are three rights that must be protected, not just singly but together and at the same time.

- There is the right to individual privacy, so that no harm or embarrassment comes to a person from any use to which his records may be put.
- There is furthermore the right of a person to protection of his health, through early identification of the causes of potentially preventable diseases to which he may be exposed. (For this purpose he may have reason to expect that his records, and those of his confreres, will be used to the best possible advantage.)
- Finally there is the right of the custodian of these records to be protected when he permits them to be used for appropriate studies designed to reduce disease, in ways which are consistent with the confidentiality requirements of the relevant statistics acts.

I submit that these are not competing principles. It is possible and practical now to employ them all. To emphasize any one of the principles to the exclusion of the others is dangerous, and in particular to emphasize the first of them at the expense of the second and third does disservice to those people who have a need for protection against avoidable risks. (Newcombe, 1977)

The framework of this discussion is now fairly clear. In our society, strong emphasis is placed on the individual's right to control the dissemination and use of personal information. At the same time, effective arguments can be made for the use of personal information in the public interest. Before looking in more detail at how an evaluation of competing interests can reasonably be carried out, some discussion of the significance of microelectronic technology is necessary.

#### 4. Significance Of Microelectronic Technology

Canadian personal records of occupation are, according to Newcombe (1977), "increasingly centralized and ... increasingly automated", and he predicts this trend will continue. He cites the Unemployment Insurance Commission with machine readable records of all people in the workforce contributing to unemployment insurance; the records show whenever someone is hired for the first time or changes jobs. In addition, income tax returns show name of employer and some information on occupation.

Newcombe describes the Canadian vital records system as "probably as good as any in the world"; it provides a

centralized and computerized mortality data base. Ontario Health Insurance Plan records are also held electronically (Krever, 1980) and it is probably safe to say that all provincial health insurance plans (medical and hospital care) are similarly using electronic technology. As a result, the only barriers to linking large amounts of personal information are organizational (including legal, political, ethical and jurisdictional), not technological. As Newcombe (1977) states: "for the first time in history, it would be possible to follow-up the whole of the Canadian labour force, and to monitor the whole of Canadian industry for delayed risks."

The significant fact emanating from all these records being held in electronic systems is that the problems and risks inherent in any records systems are heightened. For example: (the following points are summarized from the Krever Report, 1980)

- data held electronically are very dense. This permits a records thief to be non-selective. Thousands of records can be stolen (e.g. on disk or tape) and reviewed on compatible devices elsewhere. Such non-selective access to a large number of records would be impossible in a paper system.
- Theft can be invisible by accessing data on a screen, or transmitting data to another terminal or file unknown to the guardian of the data, without necessitating theft of a disk or tape, and without



altering the source data.

- Input records, if not carefully handled and destroyed, can be accessed unknowingly.<sup>1</sup>
- Large numbers of copies of data can be made quickly on high speed printers or computer output microfilm devices, which makes copying large amounts of data much easier than is possible with paper records.
- Data can be deleted, change or added to invisibly. No trace of overwriting remains in electronic systems; this is much more difficult in paper systems.
- Linkage across different data bases (e.g. OHIP and Ontario WCB records) can be achieved.

A number of authorities have concluded that electronic technology in and of itself does not create a privacy/confidentiality problem. Westin (1979) states that the National Academy of Sciences Project on Computer Databanks<sup>2</sup> reported that, contrary to worries, computerization of personal data by organizations had not led inevitably to data practices that threaten the privacy and due process rights of record

---

<sup>1</sup> Krever Commission, 1980: two incidents are reported . Discarded OHIP (Ontario Health Insurance Plan) claim cards, en route to destruction, were intercepted in an unutilated form and delivered to the Ontario Medical Association office. Similarly, in June, 1978, some 3600 copies of Wellesley Hospital pathology reports in an unutilated form were blowing throughout Toronto's downtown, having apparently escaped from a plastic bag which had been loaded onto a disposal company's truck.

<sup>2</sup> Westin, A.F. and M.A. Baker. Databanks in a Free Society, New York Quadrangle, 1972 cited in Westin, 1979.

subjects. Specifically, they did not find automatic increases, with the implementation of electronic data processing (EDP), in the collection of more detailed and wide-ranging personal information, or the sharing of data between organizations more widely than previously, or the creation of secret or inaccessible files where previously individual rights of access had existed. They did find the creation of more up-to-date and complete records on individuals; faster responses to inquiries about persons; more extensive manipulation and use of stored information; the creation or expansion of networks for data exchange among organizations within particular fields of activity; and the creation of some large data bases that would not have been feasible without automation.

The U.S. Privacy Commission (1977) describes the impact of the technology this way:

Instantaneous availability of information on employees at many locations may centralize some decisions now made locally; it certainly will raise the significance of need-to-know criteria in any policy governing disclosure of records within a firm. Centralization of files also increases the capability of organizations to respond to external requests for information about their employees. ... easy retrieval may intensify pressures to make information available for purposes other than those for which they were originally collected.

Similarly, the Krever Report (1980) states

Computers themselves are not the problem; they have simply made the problem more clear, more immediate, affecting more of us, and putting more at stake.... computers bring into stark relief the problems faced in any records system. It just happens that the very efficiency and nature of computer systems makes these

problems more evident.

Once the responsibility to protect personal information is recognized, computer data systems can be made very secure through, for example, use of passwords, separate files for various parts of the information, and time and error toleration limits. This kind of security may surpass the traditional locked door protection of paper data systems.

##### 5. THE UNIQUE PERSONAL IDENTIFIER ISSUE

The issue of a unique personal identifier is useful to discuss at this point because it involves many of the same concerns that computerized data bases raise.

The purpose of a system of unique (one in a lifetime) personal identifiers is to enable files from different sources to be linked more accurately and rapidly, whether for research or administrative uses (Krever, 1980). Inaccurate linking of files can result in problems for individuals incorrectly identified (e.g. denial of credit, employment refusal) as well as distort research results, particularly a problem where small numbers of cases or exposures are involved. The concept of a personal register, permitting a multitude of life events on any individual to be resurrected economically and easily causes controversy however. As Krever (1980) states: "The problem with record linkage is a fear that government will know everything, or can know everything about all the members of society."

Potentially, such access to information could be abused. Westin (1976) states "What we conclude is that the main problem today in computerized health data systems is potential harm ... these possibilities of misuse have not been taken into account and dealt with effectively by the managers of such computerized systems"(emphasis in original).

This larger social implication is also evident in Westin (1979):

... societies with regard for individual rights can shape the future uses of technology by powerful organizations, rather than to allow machine and bureaucratic efficiencies to misshape organizational life along non-democratic pathways. Much is at stake in our electronic civilization.

Krever (1980) reports that "West Germany,...., in 1977 withdrew its plans to introduce a unique personal identifier" as a result of these kinds of public concerns, and that the United States "recently rejected a proposal to use the social security number on census forms to facilitate linkage" for the same reasons.

Linkage of files is possible without a unique personal identifier. The obvious example is the system in use at Statistics Canada, using a group of identifying characteristics which results in fast, reliable, inexpensive and accurate linkage (See discussion in chapter one above). It does require that more identifying data be stored than would be required in a unique personal identifier system, and hence is more costly. It also retains the possibility of inaccurate linkages, which is

less likely with a unique identifier.

In summary, the problems raised by the concept of a unique personal identifier are not specifically tied to the implementation of the program itself; potential for abuse of personal records by linking independent sets of records exists already, as is well documented in the Krever report (1980). The problem is that, like computerized data bases, the use of unique personal identifiers may permit faster, easier, and larger scale abuses. In other words, the technology of a unique personal identifier simply puts the problem of improper linkages in a clearer light and makes it "more immediate, affecting more of us, and putting more at stake", to quote Krever's (1980) comments on computer technology once again.

The significance of both the unique identifier and computerized data bases is not the technology itself in either case, but what information is held using them and the nature and quality of the controls over their use.

#### 6. Some Proposals For Solutions To The Technology Problems

No one proposes not using computerized data systems as a solution to the problems listed above. It is clear that electronic technology is here to stay.

Proposals for dealing with the risks of large, centralized data systems highlighted by the impact of computer technology are two pronged:

- fair information selection : review of data collected or to be collected and held to ensure that it is necessary and relevant to the purpose for which it is collected, accurate, complete and timely. If it does not meet these criteria it should not be held.
- secure information management : ensure the security and confidentiality of records by establishing the necessary administrative, technical and physical safeguards in the records system.

These principles are incorporated in the following reports:

U.S. Privacy Act of 1974 (subsections 3(e)(1), (5) and (10)) (U.S. Privacy Protection Study Commission, 1977) and reiterated in the 1977 U.S. Government report of the Privacy Protection Study Commission;

Records, Computers and the Rights of Citizens: the Report of the Secretary's Advisory Committee on Automated Personal Data Systems, U.S. Department of H.E.W., 1973;

Ethical Considerations in Research Involving Human Subjects, Report Number 6, Medical Research Council of Canada (1978) (addresses second issue above only);

Computer Science and Technology: Computers, Personnel Administration, and Citizen Rights, Westin, A. for U.S. Department of Commerce, 1979;

the Kreyer Commission report, 1980 (recommendations 36-42).

This list is not necessarily exhaustive.

A slightly different but potentially useful formulation of basic principles is summarized by Reinert (1981) in the following way:

The [U.S.] Privacy Commission established three general policy goals: 1) minimizing intrusiveness 2) maximizing fairness and 3) creating legitimate expectations of confidentiality. These goals correspond roughly to three stages of the record keeping process: 1) collection 2) use and 3) dissemination of information.

Establishing and maintaining these principles in any records system requires a commitment of time and money. Kreyer notes that the lack of detection of violations of the Ontario health data systems is not necessarily good:

From the data guardian's point of view this [lack of detection of system violations] may be considered less than lucky since the absence of documented breaching of the security system creates the feeling that the issue is exaggerated, that the cost is not worth it, or that the precautions taken are adequate. To a certain extent we have been lulled into a false sense of security.

and

Only if the responsibility of the data guardian is recognized, however, will the cost of instituting security measures seem justified. (Kreyer, 1980)

With respect to the unique personal identifier, it is not a

given that the technology will be introduced. Opinion is divided on the necessity of such a system and may in fact be leaning away from supporting its institution (see the discussion above, specifically recent actions of West Germany and the USA).

Regardless of whether or not unique identifiers are the mechanism for record linkage however, records are and will be linked and solutions are aimed primarily at addressing authorization to link files rather than use of unique identifiers. Sweden established the Data Inspection Board in 1973 which "regulates the collection and dissemination of data stored on computers" (Krever, 1980). These responsibilities include how a data bank is maintained and to whom information may be disseminated. Krever (1980) also states "Similar data protection agencies have been established or recommended in France, West Germany, Holland, and the United Kingdom as a prerequisite to implementing a unique identifier system." Krever recommends a similar process for Ontario if a unique identifier is adopted, stating "The primary and crucial function of a central agency would be to approve data linkage. In many respects this function resembles the role of the human experimentation committees ... dealing with research, except that the procedures would apply to any group or individual, including government, requesting linkage of data."

Given that systems exist to link records accurately and efficiently without the aid of a unique identifier, the question remains whether the body Krever recommends should be established whether or not unique personal identifiers are introduced.



## 7. Special Issues Relating To Employer-held Records

Employer-held personal records consist of personnel records, containing such information as personal characteristics (e.g. name, age, sex, address, birth date, marital status, dependents, etc.), recruiting and hiring data (e.g. education, employment, medical, military, conviction history; references, test scores, interview data), work and educational history within the organization, and benefit plans enrolled in and used (from Westin, 1979), and occupational health and safety information, including medical exam results, compensation claims, results of any tests done or exposure monitoring. Westin (1979) makes the case that employee records are very similar to education and health care records because of the continuing relationship and the recognized right for the employer to record personal information extensively. Westin contrasts these kinds of records to one-time collection of information situations, such as job applications, applications for credit or licences. Reinert (1981) states "The [U.S.] Privacy Commission found that employment records were the most diverse, perhaps the most important, and in many ways the most problematic of the record keeping systems it studied." <sup>1</sup> Reinert attributes this importance and diversity to the central role of employment in people's lives and the diversity of

---

<sup>1</sup> Reinert (1981) cites the statement of R. Plessner, former General Counsel, Privacy Protection Study Commission at the [U.S.] Department of Labour Hearings on Workplace Privacy, 1980. Transcripts available at Department of Labour, Washington, D.C., 45 Federal Register 8780 (1980).

management functions for which records can be used.

Researchers may have an interest in access to employer-held records for a number of reasons. The U.S. National Institute on Occupational Safety and Health (NIOSH) has argued for access. They state:

In the occupational health and safety setting, data kept by the employers are of importance to the health of individuals as a whole. Non-disclosure of this data to the employees and qualified researchers cannot be morally or ethically defended ... Exposure, demographic and medical data provide valuable information in determining the dose-response health effects of occupational exposures on workers, developing standards, and establishing preventive measures. ... The data needed ... include exposure data, medical information, work history information and demographic data collected by the employers. <sup>1</sup>

Debate rages on two fronts on the issue of employer-held records: how much information should be held and who should have access to it. These questions are interrelated, but for simplicity will be dealt with consecutively.

The debate on whether employers should hold the extensive personal information they frequently do is fired by concern about abuse of such information by employers. Reinert (1981) classifies potential employer abuse in three categories:

- i. data gathering which is unduly intrusive due to the method of solicitation (e.g. lie detector tests), the type of information sought (e.g. political or

---

<sup>1</sup> (\*) NIOSH testimony on OSHA regulations titled, 'Access to Employer Exposure and Medical Records', November, 1979 cited in Rose, 1981.

- religious belief, sexual orientation) or the absence of informed employee consent about whether to disclose the information (e.g. employer obtaining information under false pretenses or by private investigation);
- ii. unfair information use , which "occurs whenever personal information is used as the basis for an adverse decision about an individual in a manner to which the individual did not consent when disclosing". Reinert notes "Currently, the most troublesome form of such discrimination involves medical records which are used to screen out applicants who are physically capable of performing jobs ..." (Reinert, 1981);
  - iii. breach of confidentiality , consisting of "... disclosure of employee information to a third party by the employer without notice to and consent of the employee. ... [This] may be the most serious form of privacy abuse, because it violates such expectations of privacy and can lead to personal or economic harm to the employee." (Reinert, 1981)

These types of abuse are all related to a particular kind of use of information, that is, use of the personal data collected to make decisions which may affect the individual who the data concerns.

As Reinert has noted, an important area of potential abuse involves employer-held medical records. All authors are vehement that personal medical information held by the employer's occupational health department is open to abuse if it

is made available to non-medical employees in a position to make decisions affecting the individuals on whom information is held. Medical staff are directed to ensure the confidentiality of such personal medical information. Krever (1980) states that the results of an examination of a prospective (or present) employee should be communicated to the employer only in terms of "fitness to work". Presumably any limitations would be expressed in terms of fitness to hold particular jobs and not others. This of course requires that the medical staff be familiar with the specific demands of the various jobs. Medical staff are also responsible to alert management to any source of hazard in the workplace which is causing or has potential to cause health problems.

Unless this administrative distinction can be made within the employer's operation, then it is not justifiable to hold personal medical data. This distinction is supported by the code of ethics of the American Occupational Medicine Association, which states that a physician providing occupational medical services

treats as confidential whatever is learned about individuals served, releasing information only when required by law or by over-riding public health considerations, or to other physicians at the request of the individual...; and should recognize that employers are entitled to counsel about the medical fitness of individuals in relation to work, but are not entitled to a diagnosis or details of a specific nature.<sup>1</sup>

---

<sup>1</sup> Point 7, Code of Ethical Conduct for Physicians Providing Occupational Medical Services, AOMA, 1976 cited in Rose, 1981.

The concern of trade unions and other investigators is that this standard of practice is a very delicate one, given that the occupational medical services staff are employees also, not an independent third party. Krever (1980) states

These health professionals face a conflict between their duty with respect to the requirements of confidentiality of patient information and their duty to obey the instructions of their employers. ... This is a special problem for the occupational health nurse who is not perceived by our society to have as high a status as the physician, and, on the available evidence, is therefore more likely to be subject to pressure from the employer to reveal confidential information.

Krever reports testimony from the personnel manager of Dare Foods Ltd. to support this, as well as by individual occupational health nurses and their Association. He also cites a number of arbitration cases where physicians passed on to the employer medical information without the consent of the employee in question. Krever concludes by stating that all employees, including first aid attendants and clerks handling and storing records, have a responsibility to respect the confidentiality of medical information, a responsibility which transcends the duty to obey instructions to reveal information held in confidence. This supports the position that medical records should not be available for input to management decision-making.

Access to union-held records has not been addressed because, as was demonstrated in chapter 2, unions simply do not hold extensive personal information on their members. If and when unions begin to collect personal information comparable to

that held by employers, either for administrative purposes or as the result of investment in health and safety programs run by the union, then the issues discussed above regarding employer responsibilities will apply to unions as well.

Workers' Compensation claims information held by the provincial boards is also subject to the same requirements of confidentiality described above. Since the WCB is a separate and quasi-governmental agency, such practices appear to have been established and respected. Public discussion has been aroused recently however over the issue of a claimant's lack of access to his/her own records. Steeves (1982) reports on a landmark decision in the B.C. Court of Appeal in July 1981 which directed that workers appealing board decisions must be provided access to their files in order to be given fair opportunity to correct or contradict statements or evidence used in decisions affecting him/her. The implications of this decision for WCB practices are still being determined; an area of particular dispute is whether the employer requires the worker's consent in order to see a claims file which is under appeal.

So far, we have discussed only administrative uses of personal information. As Newcombe (1977) states

Ideally, a clear distinction ought to be made between the use of records for purely statistical purposes, which affect no one directly, and their use by administrators to arrive at decisions capable of affecting the individual. The two sorts of activity are quite different, even where the same records happen to be employed for both purposes.

Once this distinction is made, it is possible to focus

on the question of importance for this paper, that is, access to records by researchers for non-administrative uses.

#### 8. Guidelines For A Balancing Of Interests

Researchers may be interested in nominal roll data and/or more specific exposure information (jobs held, duration, environmental monitoring records, etc.) or medical information. Newcombe (1977) recounts, as an example, a story where confidentiality is given as a reason by an employer to block researcher access to such records. Newcombe is clearly concerned that, in the name of protecting confidentiality of records, important hazards will not be identified. This concern is echoed by Ken Valentine (1977), Director of Safety and Health for the Canadian National office of the United Steelworkers of America. Valentine states "... I suggest too many people use the word 'confidentiality' when they really mean secrecy. They just don't want society, or their workers, to be aware of the full extent of hazards on the job."

What solutions have been put forward to balance the concern for confidentiality with the public interest served by research in access to personal records?

A common guideline (Westin, 1979; U.S. Privacy Commission, 1977; Reinert, 1981; Ahrens, 1981; Fredgant, 1981) proposes employee consent and/or advisement for all disclosures of information. U.S. Occupational Safety and Health Act (OSHA)

1979 regulations provide that access to employer-held medical and exposure records is available to the individual workers themselves, to their designated representatives (e.g. trade union representatives) as long as written consent is provided by the worker whose record is to be examined, and to OSHA and NIOSH without consent from the individual(s) involved (Rose, 1981). There appears to be trade union support for this arrangement<sup>1</sup>. Specific opposition was voiced by an employer's association quoted by Rose (1981):

To be meaningful the consent required must be informed. ... The present regulation makes absolutely no provision for consent with respect to request for records by OSHA and NIOSH, and such a version is totally inconsistent with the privacy interests of employees.

... the failure of some employers to respect the privacy of some employees is no reason for a similar abuse on the part of OSHA and NIOSH, much less the type of massive intrusions to personal privacy and wholesale breach of confidentiality inherent in this regulation. ... No matter how compelling the need may appear for government to obtain the data on occupational health and safety issues in order to develop standards applicable to the workplace, ... , the records could be used for enforcement purposes. ... The employers had not subjected their record keeping practices to the type of protections that would be indicated if the employer knew that the records could be used against him by OSHA for purposes of the enforcement of the Act.<sup>2</sup>

---

<sup>1</sup> U.S. Steelworkers of America Brief on OSHA-NIOSH Access to Employee Exposure and Medical Records, March 1979 in Rose, 1981.

<sup>2</sup> Motor Vehicle Manufacturers Association of the U.S., Inc., March 1979 in Rose, 1981.



Epidemiologists have argued that requiring consent will certainly make research difficult and potentially impossible (Gordis and Gold, 1980; NIOSH testimony, November, 1979 in Rose, 1981; Krever, 1980). These difficulties arise in a number of ways: the research question may arise long after many of the employees have left the employer, making consent difficult or impossible to obtain; it may be necessary to have some information without consent in order to identify the people who need to be contacted about consenting to participate further; where sufficient data are already in hand, the effort and costs of obtaining consent for data used from each subject may be prohibitive; even if consent was sought, the volunteer nature of the consenting population might compromise the results.

Krever (1980), in weighing the issue, emphasized the fact that "research information, unless it is abused, is not used to make decisions about an individual, such as those denying or conferring a benefit." He recommended that medical information be made available without the consent of the patient to researchers where the information is indispensable to the project, the project is of sufficient importance to justify the breach of privacy (as determined by a human experimentation committee) and that adequate provisions are made for maintenance of the confidentiality of the data.

The Medical Research Council of Canada (MRC) took a similar position:

The increasingly frequent use, for research, of medical or personal records maintained in central registries ... raises the question of

confidentiality. The principles governing the use of such data must take into account the fact that it may be impossible to get prior consent for use of these records in every instance.

... The ultimate responsibility for the control of records must lie with the director of the research group. ... Every effort should be made to enforce the security of records and to regulate their storage and use. (MRC, 1978)

The new Canadian Human Rights Act also supports this position. It specifies procedures for consent and access to individual personal data held by the federal government. Consent is not required from the individuals where the use of the data is for statistical and research purposes only (Rowebottom, 1979). Rowebottom (1979) comments that these provisions resemble the U.S. Privacy Act "but because of the sharp distinction between administrative and statistical use of data the Canadian Act will facilitate rather than inhibit research."

Where consent is not practicable, Krever (1980) nevertheless urges researchers to make the subject and the public aware of what uses the information accessed is put and what protection is given to the information held. Although Krever's remarks are addressed specifically to the release of medical information from medical institutions, they are clear enough in the principles they express to be applied to employer-held medical and personnel records. The MRC wording presented above concurs with Krever's recommendations and is not limited

in its application.

The conclusions from this review of the confidentiality issue can be summarized in a few principles and the caveat that the application of these principles may not always be easy.

The principles are these:

- i. Records should be relevant, accurate, and timely and the subject of the record should be aware of what is held, how it is used, and should be able to review, copy and either correct or add a statement if he/she contests information held.
- ii. Disclosure of any personal information to a third party should, as a rule, be only with the informed consent of the subject of the record. Research uses of records can be an exception to this rule where all of the following criteria are met:
  - it is not practical to obtain consent from each subject;
  - the information is indispensable to the research project;
  - the project is of sufficient importance to justify the breach of privacy;<sup>1</sup>

---

<sup>1</sup> The evaluation of significance of the project (i.e. the public interest) in relation to the individual interest in privacy and confidentiality should not be in the hands of researchers alone. Any decision regarding record linkage should be made by a board which represents a spectrum of social interests (see Krever, 1980 and his discussion of the Swedish Data Inspection Board).

- no information made available to the research project is used in any way which will identify an individual, or permit any impact for good or ill on any of the individuals on whom information is acquired, unless there is critical medical information affecting the life or health of the individual on the basis of which action should be taken;
- the data is held in a way which is administratively, technically and physically secure in order to assure confidentiality.

#### C. POLICY OPTIONS

Section B above presented possible mechanisms for improving long term retention of employment nominal roll information. This section will attempt briefly to identify probable routes for improvement given the social-political context in B.C.

The model used to evaluate the various mechanisms is drawn from Hall et al., 1975. They propose three main criteria against which any issue is assessed in determining the priority it is given in the decision-making arena. These criteria are legitimacy, feasibility and support. They propose that any issue can be scored against each of these items and its likely progress estimated.

## 1. The Collective Bargaining Arena

About forty-five per cent of B.C. workers are covered by collective agreements (British Columbia, 1982). Requiring long term retention of nominal roll information is highly feasible in the sense that fairly specific contract language can be imagined which would cover the fair collection and storage (by either or both parties, or a third party) of such information in an efficient manner. Resources required are not particularly large. Administrative capabilities for carrying out the process exist both on the employer's side and to a lesser extent on the union's. The only weak area with respect to feasibility is the collaboration between employer and union such a contract clause would represent. The public tone of labour relations in this province is primarily adversarial and the expression of common interest in long term health issues and potential cooperation in the use of the data may appear to be in contrast to the prevailing climate. In fact, however, there are examples of collaboration between unions and management on health issues (for example, joint health studies, employee assistance programs) and therefore the feasibility of this option is in fact quite high.

Legitimacy concerns the question "is this an issue with which the party in question should be concerned?" The answer is not a clear one for either employers or unions with respect to occupational health research and long term retention of records. There are a number of factors involved.

First, occupational diseases are a fairly new issue, except

in particular industries where long term hazards have been recognized for half a century or more, or have recently received extensive publicity. This was discussed briefly in chapter 1 and more fully in Appendix B. As a result, unions and employers may simply be uninformed or unaware of the potential for long-term health problems related to the production process in which they are involved, and therefore consider them to be of no concern in their policy making or contract negotiations.

Second, the employer has an economic incentive (see Appendix C) to deal with them as not relevant in this industry or as someone else's problem. (Note that the strength of this incentive varies with the expectations of the employer to be in business in the same community for the next twenty to fifty years, and other factors.) One of the ways of deflecting the issue is to present the health problems as problems of particular individuals, due to genetic predisposition, personal habits or other factors unrelated to the workplace. Then the issues surrounding the ill-health become issues for the social welfare systems, the clinical medical systems and clinical and laboratory research.

Thirdly, the issue of long term retention of nominal roll information may have fairly low levels of legitimacy with both unions and employers to the extent that it is perceived as infringing on privacy and confidentiality of employees/members. This issue may be sensitive enough that one or neither party wants to stir up trouble by presenting proposals which might be perceived in this way.

Overall, legitimacy of this issue for unions and employers may be fairly low.

Support involves both "whose discontents and whose satisfactions are involved" (Hall et al., 1975) and the general reservoir of support at a given time and the anticipated impact of the issue on that reservoir.

These criteria may be more important for unions than employers, since unions are political organizations and maintaining support of a majority of members must necessarily be an almost constant objective of union leadership.

Bacow (1980) points out that occupational health may be a high priority to only a small section of the union membership, either because of limited areas of hazardous exposures, or because potentially hazardous jobs tend to be assigned to low seniority members who may be younger and/or transient, and therefore less aware of or concerned about hazardous conditions and less influential in the union, or because of a lack of information and understanding among union members generally. As a result, it may be politically unwise for a union leadership to give this issue priority in contract negotiations over issues of concern to a larger section of the union's membership (e.g. wages, other benefits, technological change, retraining, etc.).

The issue may also become important because of its effect at the margin in a union election. It may be sufficient to either swing votes with or against the incumbents.

Employers may also be concerned about support on an issue

like this among their management staff or among the members of the board of directors. The importance and immediacy of support or non-support may be less apparent than in unions but the smooth running of an organization depends upon both reservoirs of support and balancing of interests among groups within the enterprise. Good managers will assess the support for a particular proposal before undertaking it. Like unions, support on this particular issue within the employer's organization will depend upon the level of information and education about it and the extent to which other project or goals are seen to be jeopardized by it.

Support for long term retention of records is likely to be fairly low in both employer and union organizations, except in those industries where health concerns have become a significant issue.

## 2. The Legislative And Regulatory Arena

Legislative and regulatory mechanisms for improving the retention of nominal roll information were described in sections A. 1. and 2. above. The technical feasibility of making changes to various pieces of tax, employment standards or social security legislation or health and safety regulations is high; the administrative feasibility of getting amendments on legislative agendas, given the overburden of legislative demands in most jurisdictions, and assuring compliance with such legislation is not particularly high. As was described above, existing record retention rules are disjointed and unclear.



Hope for improvement at the federal level came primarily from the now defunct Office for the Reduction of Paperburden. Their recommendation limited retention to six years for tax records; there was apparently no consideration of long term (i.e. twenty years or more) retention of any records which might constitute a nominal roll. These recommendations, aimed at cleaning up record retention requirements, have not yet been acted upon. There is no indication that the issue is being addressed in the provincial legislature in B.C.

The technical feasibility of changes to provincial health and safety regulations is also high; language can be conceived which would not be at odds with existing provisions of the health and safety regulations. Administrative feasibility is also probably fairly high. Getting amendments to the health and safety regulations requires only that the Board hold a public hearing prior to any changes; the Board does not require the approval of the legislature for changes to the regulations. Ensuring compliance with such regulations is also administratively plausible, particularly if the requirement was limited to particular industries and/or sizes of employers.

The legitimacy of the issue for federal or provincial legislators is probably fairly low. Particular industrial health problems have from time to time become issues in various legislatures (e.g. asbestos mines in Quebec, uranium mining in Ontario, Saskatchewan and B.C.), but these have usually been raised after the fact and have not led in an organized way to desire for widespread occupational monitoring for potential

hazards.

Within agencies responsible for health and safety regulation the legitimacy of the issue is undoubtedly higher, since the purpose of the agency is specific to these concerns. However, disease is still less focal in these agencies than is injury (see Appendix C), although interest is growing in disease monitoring.

This shift in interest is reflected in a growing number of official and public bodies who have as an area of interest occupational health issues; they may be expected to give rise to increasing discussion and promotion of long term research planning, thus raising the legitimacy of new legislation or regulation. Some of the bodies which might play this legitimizing role are: the new (1982) joint union-employer regulation advisory committee at the B.C. compensation board; the Occupational and Environmental Health Research Unit at Statistics Canada; the Canadian Centre for Occupational Health and Safety; university and college researchers and teachers involved in occupational health and safety questions (in B.C. these include research groups at Simon Fraser University, University of British Columbia, teachers and students in the new two year occupational health and safety program at the B.C. Institute of Technology and in individual courses at the Capilano College labour studies program); and public interest groups focussing on occupational health and safety, such as Vancouver Committee on Occupational Safety and Health (VanCOSH) and Windsor Occupational Safety and Health group (WOSH) in

Ontario. As these constituencies mature, increase their communication with one another and identify common problems and concerns, significant support for long term retention of nominal roll information for research puposes could be created. Given the location in society of many of the people concerned with the issue, significant influence in decision making institutions and among decision takers (through formal and informal means) can be expected.

This legitimizing activity will probably progress more quickly at the health and safety agency level. On legislative agendas, this issue will probably remain a minor item, and would become incorporated only as part of other housecleaning activities like the recommendations from the Office on the Reduction of Paperburden mentioned above. The constituency aware and concerned is small, and in relative terms, is likely to remain small. The possibility does exist that should the issue make it onto the political agenda, it would become publicly significant because of opposition rather than support. This opposition could arise from the privacy/confidentiality concerns mentioned earlier or from the paperburden concern which has already been heard from in Ottawa. The fate of legislative proposals would be determined by the size and nature of both opposition and supporting groups, and their perceived impact on marginal votes by the various political parties. Certainly at this time it is not certain that politicians would perceive sufficient support for the legislative change of the nature proposed to risk supporting it.

Health and safety agencies might, however, feel they have sufficient support within their staff and may feel they can develop support among the informed unions and employers with whom they consult, to make the necessary regulatory changes more easily than would legislators. These agencies are buffered from the direct impact of the electoral process and may feel their mandate gives them authority to take action with the support of only an informed minority. Support would be qualified by the fact of the historical prominence accident and injury programs have had over disease and by the possibility that the same interests who would rally against legislative action would organize against similar regulatory action. Political pressure can be exercised on the quasi-independent compensation board; the extent to which it is exercised or responded to depends upon the political climate of the day and the objectives of the Board's top administration.

The problems of support may in fact be the circumstances dictating the freeze on implementation of section 78 of the B.C. WCB health and safety regulations. This section, the occupational medicine section, was included in the most recent amendments and reflects the increasing awareness and concern in the last fifteen years. Although the section is printed in the book of regulations, it is not officially in effect and is not enforced.

### 3. Policy Options: Conclusion

In summary, the most likely route for policy implementation regarding long term retention of nominal roll information for occupational health research purposes is via health and safety regulation. This route is feasible and is likely to gain legitimacy with increasing activity by various interest groups and increased discussion between the health and safety agencies and outside interest groups. There may be opposition from some constituencies but this will be less critical to the quasi-independent regulatory agency than it would be to an elected body. The potential support for action by a regulatory agency, both within their own organizations and among the unions and employers they serve, probably still needs to be developed through formal and informal education and discussion, given that occupational disease research is in a fairly young stage of development in Canada.

# BIBLIOGRAPHY

1. Abdellah, F.G., E. Levine. Better Patient Care Through Nursing Research. New York:MacMillan, 1965.
2. Acheson, E.D. "Record Linkage and the identification of Long Term Environmental Hazards", in Long Term Hazards from Environmental Chemicals , Proc. R. Soc. Lond. B. 205 , 165-178. 1979A.
3. Acheson, E.D. "Some Aspects of the Use of Record Linkage in Health Research in the United Kingdom", NCIC Workshop on Computerized Record Linkage in Cancer Epidemiology, Statistics Canada, Ottawa. 1979B.
4. Ahrens, Michele P. "Liability Waiting to Strike: Violation of an Employee's Privacy through Disclosure of Records", Loyola (L.A.) Law Review, 14 (2), 385-404. 1981.
5. Americal Cancer Society. Cancer Facts and Figures . 1975.
6. Anderson, D.O. "The Epidemiologist's Dilemma", Can. Med. Assn. J., 1019-1027. 1965.
7. Anderson, T.W., D. Enarson, V. Embree. Chlorophenate Feasibility Study Report . Local publication, limited circulation, 1981.
8. Anson-Cartwright, R.M. and R.T. Hollingshead. Records Retention for Tax and Other Purposes (second ed.). Toronto, Ont.: Richard De Boo Ltd., 1980.
9. Ashford, N.A. Crisis in the Workplace: Occupational Disease and Injury . A Report to the Ford Foundation. Cambridge, Mass.: MIT Press, 1976.
10. Aykroyd, Colin. "A Summary of Developments in Occupational Health and Safety", B.C. Labour Research Bulletin, 6 (6), 24-31. B.C. Ministry of Labour, 1978.
11. Bacow, L.S. Bargaining for Job Safety and Health . Cambridge, Mass.: MIT Press, 1980.
12. Barker, D.J.P. and G. Rose. Epidemiology in Medical Practice . New York: Churchill Livingstone Inc., 1976.
13. Barrett-Conner, E. et al., eds. Epidemiology for the Infection Control Nurse . St. Louis: W. Mosby Co., 1978.
14. Bates, R.R. "Preventing Occupational Cancer",

- Environmental Health Perspectives, 28 , 303-310. 1979.
15. British Columbia. B.C. Labour Directory, 1982 .  
Victoria: Ministry of Labour, 1982.
  16. British Columbia. Workers' Compensation Act ,  
consolidated 1976. Victoria: Government Printers.
  17. British Columbia Health Association. Discussion Paper on  
the Confidentiality of Health Information . Unbound,  
limited circulation. Vancouver, 1982.
  18. British Columbia Ministry of Labour. Negotiated Working  
Conditions . Victoria: Government Printers, 1981.
  19. British Columbia Workers' Compensation Board. Industrial  
Health and Safety Regulations . 1978.
  20. Calkins, D.R. et al. "Identification, Characterization  
and Control of Potential Human Carcinogens: A Framework  
for Federal Decision-Making", (U.S.) JNCI, 64 (1), 169-76,  
1980.
  21. Canada, Environmental Protection Service. Chlorophenols  
and Their Impurities in the Canadian Environment . By  
P.A. Jones. Environment Canada, Doc.No.En 46-3/81-2,  
1981.
  22. Chalmers, Alan F. "Epidemiology and the Scientific  
Method", Int. J. Health Serv., 12(4), 659-666, 1982.
  23. Chemical Abstract Services. "Registry passes 4-million  
mark; uses grow", CAS Rep., 7 (2), 1978.
  24. Coffman, Kimberly. "Cost of Records Retention Sparks Push  
for Reform of Federal Storage Rules", Canadian Office, 26-  
27, September 1979.
  25. Corwin, E.H.L. Ecology of Health . New York:  
Commonwealth Fund, 1949.
  26. Detels, R. "The Need for Epidemiologists", JAMA, 242  
(15), 1644-1646, 1978.
  27. Discher, D.P. et al. Pilot Study for Development of an  
Occupational Disease Surveillance Method . (U.S.) HEW  
Publication No. (NIOSH) 75-162, 1975.
  28. Doll, R. and A.B. Hill. "Smoking and Carcinoma of the  
Lung: A Preliminary Report", Brit. Med. J., 2 : 739-748.  
1950.
  29. Doll, R. "Pott and the Prospects for Prevention", Brit.  
J. Cancer, 32 , 263-72, 1975.

30. Doll, R. "Strategy for Detection of Cancer Hazards to Man", Nature, 265 , 589-596, 1977.
31. Economic Council of Canada. Reforming Regulation. Ottawa: The Council. Doc. No. EC 22-93/1981E, 1981.
32. Elwood, J.M. and J.H. Elwood. Epidemiology of Anencephalus and Spina Bifida . Oxford: Oxford Univ. Press, 1980.
33. Epstein, Samuel S. The Politics of Cancer . San Francisco: Sierra Club Books, 1978.
34. Fox, J.P., C.E. Hall and L.R. Elveback. Epidemiology: Man and Disease . MacMillan, 1970.
35. Fredgant, Perry R. "Confidentiality of Personnel Files in the Private Sector", U.C. Davis Law Review, 15(2) , 473-492, 1981.
36. Friedman, Gary D. Primer of Epidemiology . McGraw-Hill Inc., 1974.
37. Gordis, L., E. Gold, R. Seltser. "Privacy Protection in Epidemiological and Medical Research: A Challenge and a Responsibility", Amer. J. of Epi., 105 , 163-168, 1977.
38. Gordis, Leon and Ellen Gold. "Privacy, Confidentiality and the Use of Medical Records in Research", Science, 207 , 153-156, 1980.
39. Gordon, J.B., A. Akman and M. Brooks. Industrial Safety Statistics: A Re-examination . New York: Praeger, 1971.
40. Great Britain. Health and Safety at Work: Report of the Committee 1970-1972. Lord Robens, chairman. HMSO, Cmnd. 5034. 1972A.
41. Great Britain. Report of th Committee on Privacy . (The Younger Report) HMSO, Cmnd. 5012, 1972B.
42. Hall, Phoebe, H. Land, R. Parker, A. Webb. Change, Choice, and Conflict in Social Policy . London: Heinemann, 1975.
43. Hazards at Work: Law and the Workplace , seminar. C. Fairclough, ed. of transcript. Toronto, Ont.: Corpus Info. Services, 1977.
44. Higginson, J. "A Hazardous Society? Individual versus Community Responsibility in Cancer Prevention", AJPH, 66 (4), 359-366, 1976.



45. Hillway, T. Introduction to Research , 2nd ed. Boston: Houghton Mifflin Co., 1956.
46. Holland, W.H. and L. Karhausen, eds. Health Care and Epidemiology .Cambridge: University Press, 1978.
47. Hushion, Olgilvie Associates Ltd. An Assessment of the Effectiveness of Government Decision-Making Processes in the Field of Occupational Health and Safety . Technical Report No. 5. Ottawa: Economic Council of Canada, 1981.
48. Ison, Terence G. "The Dimensions of Industrial Disease, Parts I and II", CMA Journal, 118 , 200-205, 317-322, Jan. 21 and Feb. 4, 1978.
49. Jones, P.A. Chlorophenols and their Impurities in the Canadian Environment . Environment Canada, Environmental Protection Service, Doc. No. En 46-3/81-2, 1981.
50. Krever, the Honorable Mr. Justice Horace. "Confidentiality and Legislation", NCIC Workshop on Computerized Record Linkage in Cancer Epidemiology. Ottawa, Ont.: Statistics Canada, 1979.
51. Krever, the Hon. Mr. Justice Horace. Report of the Commission of Inquiry into the Confidentiality of Health Information . Ontario, 1980.
52. Labonte, R.N. Health Promotion Philosophy: From Victim Blaming to Social Responsibility: A Working Paper . In consultation with P. Susan Penfold. Vancouver: limited circulation, 1981.
53. Labour Canada. Labour Standards in Canada, 1980-81. . Ottawa, 1981.
54. Lamphier, Gary. "Government Clean-up of Records Requirements Lightens the Paperburden Load", Canadian Office, 13 (3), 10-12 + 29, March 1982.
55. Le Riche, W.H. and J. Milner. Epidemiology as Medical Ecology . Edinburgh: Churchill Livingstone, 1971.
56. Lilienfeld, A.M. Foundations of Epidemiology . New York: Oxford University Press, 1976.
57. Lilienfeld, A.M. and D.E. Lilienfeld. "The Epidemiological Fabric: I & II", Int. J. of Epi., 9 (3 & 4), 199-206, 299-304, 1980.
58. McCann, J. and B.N. Ames. "Detection of Carcinogens as Mutagens in Salmonella/Microsome Test: Assay of 300 Chemicals: Discussion", Proceedings of the National Academy of Science (USA), 73 , 950-54, 1976.

59. McCann, J. and B.N. Ames. "The Salmonella/Microsome Mutagenicity Test: Predictive Value for Animal Carcinogenicity", in Origins of Human Cancer , eds. H.H. Hiatt et al., 1431-1450. Cold Spring Harbour, N.Y., 1977.
60. MacMahon, B., T.F. Pugh and J. Ipersen. Epidemiological Methods . Boston: Little Brown and Co., 1960.
61. MacMahon, B. and T.F. Pugh. Epidemiology: Principles and Methods . Boston: Little Brown and Co., 1970.
62. Manga, P., R. Broyles, G. Reschenthaler. Occupational Health and Safety: Issues and Alternatives , Technical Report No. 6. Ottawa: Economic Council of Canada, 1981.
63. Medical Research Council of Canada. Ethics in Human Experimentation , Report No. 6. Ottawa, 1978.
64. Mishler, E.G., L.R. AmaraSingham, S.T. Hauser, R. Liem, S.D. Osherson, N.E. Waxler. Social Contexts of Health, Illness, and Patient Care. USA: Cambridge University Press, 1981.
65. National Cancer Institute of Canada (NCIC). Workshop on Computerized Record Linkage in Cancer Epidemiology , transcript of audio tapes. Ottawa: Statistics Canada, 1979.
66. Newcombe, H.B. "Records, Confidentiality, and the Detection of Delayed Industrial Risks", in Hazards at Work , transcript of proceedings of a national seminar. Toronto: Corpus Information Services, 1977.
67. Newcombe, H.B. "Record Linkage: Development and Present State of the Art in Canada ", in transcripts of audio tapes of NCIC Workshop on Computerized Record Linkage in Cancer Epidemiology . Ottawa: Statistics Canada, 1979.
68. Ontario. Report of the Commission of Inquiry into the Confidentiality of Health Information (the Krever Commission). 1980.
69. Paterson, Keith. "Theoretical Perspectives in Epidemiology: A Critical Appraisal", Aberdeen, Scotland: unpublished paper, 1981.
70. Payne, A.M. "The Scope and Methods of Epidemiology (editorial)", AJPH, 52 , 1502-4, 1962.
71. Reasons, C.E., L.L. Ross, C. Paterson. Assault on the Worker: Occupational Health and Safety in Canada . Toronto: Butterworths, 1981.

72. Reinert, T.E. "Federal Protection of Employment Record Privacy", Harvard J. on Legis., 18 , 207-251, 1981.
73. Reschenthaler, G.B. Occupational Health and Safety in Canada: The Economics and Three Case Studies . Montreal: Institute for Research in Public Policy, 1979.
74. Robens Report. Great Britain: Safety and Health at Work: Report of the Committee 1970-1972. HMSO, Cmnd. 5034. 1972A.
75. Rose, Lawrence. "Conflicting Views on the Issue of Accessibility", Occupational Health and Safety, 50 (1), 33-37, 1981.
76. Rowebottom, L.E. "Statistics Canada: The Legal Basis of Health Record Linkage", in transcript of tapes from NCIC Workshop on Computerized Record Linkage in Cancer Epidemiology. Ottawa: Statistics Canada, 1979.
77. Sands, P. "How Effective is Safety Legislation?", J. Law and Econ., 11 , 165-180, 1968.
78. Schottenfeld, David and Joanna Haas. "Carcinogens in the Workplace", CA - A Cancer Journal for Clinicians, 29 (3), 1979. Reprinted from Clinical Bulletin, 8 (2), 54-60, and 8 (3), 107-119, 1978 where the title was "The Workplace as a Cause of Cancer".
79. Sellitz, Claire; L.S. Wrightman, S.W. Cook. Research Methods in Social Relations, 3rd ed. USA: Holt, Rinehart and Winston, 1976.
80. Siemiatycki, J., N.E. Day, J. Fabry, J.A. Cooper. "Discovering Carcinogens in the Occupational Environment: A Novel Epidemiological Approach", (U.S.) JNCI, 66 (2), 217-225, 1981.
81. Smith, Bryan C. Community Health: An Epidemiological Approach New York: MacMillan, 1979.
82. Smith, M.E. "The Present State of Automated Follow-up in Canada; Part I: Methodology and Files", J. Clinical Computing, 9 (1), 1980.
83. Smith, M.E. "Long Term Follow-Up in Canada", paper presented March-April 1981, Cold Spring Harbour Laboratory, conference on Quantification of Occupational Cancer.
84. Smith, M.E. "Values of Record Linkage Studies in Identifying Populations at Genetic Risk and Relating Risk to Exposures", Progress in Genetic Research, 3, 1982A.

85. Smith, M.E. "Development of a National Record Linkage Program in Canada", paper presented at the Amer. Statistical Ass'n meeting, Cincinnati, Ohio, 1982B.
86. Sontag, Susan. Illness as Metaphor . New York: Farrar, Straus and Giroux, 1978.
87. Statistics Canada. Causes of Death . Ottawa, 1974.
88. Stebbings, James H. "Epidemiology, Public Health, and Health Surveillance around Point Sources of Pollution", Environmental Research, 25 (1), 1-7, 1981.
89. Steeves, John. Your Safety and Your Rights: Workers' Compensation, Health and Safety in B.C. Vancouver: Legal Services Society of B.C., 1982.
90. Stinden, Nancy. "Labour, Records and Archives: The Struggle for a Heritage", Archivaria, 4, 73-91, 1977.
91. Sullivan, F.M. and S.M. Barlow. "Congenital Malformations and Other Reproductive Hazards from Environmental Chemicals" in Long Term Hazards from Environmental Chemicals. R. Doll, ed. Cambridge: University Press, 1979.
92. Terris, M. "The Scope and Methods of Epidemiology", AJPH, 52 , 1371-1376, 1962.
93. Tomatis, L. " The Value of Long-Term Testing for Implementation of Primary Prevention", in Origins of Human Cancer, H.H. Hiatt et al., eds., 1339-1359. Cold Spring Harbour, N.Y.. 1977.
94. Tomatis, L., C. Agthe, H. Bortsch, J. Huff, R. Montesano, R. Aracci, E. Walker and J. Wilbourn. "Evaluation of the Carcinogenicity of Chemicals: A Review of the Monograph Program of the International Agency for Research on Cancer (1971-1977)", Cancer Res., 38, 877-885, 1978.
95. U.S. Dep't of Health, Education & Welfare. Records, Computers and the Rights of Citizens , Secretary's Advisory Committee on Automated Personal Data Systems. MIT, 1973.
96. U.S. National Institute of Environmental Health Science. Man's Health and the Environment: Some Research Needs . Report of the Task Force on Research Planning in Environmental Health Science. U.S. Dep't. of HEW, 1970.
97. U.S. Privacy Protection Study Commission. Personal Privacy in an Information Society , Report of the Commission. Wash. D.C., 1977.

98. Valentine, Ken. "Worker Health and Record Linkage" in transcript of Hazards at Work , national seminar, C. Fairclough, ed. Toronto: Corpus Information Services, 1977.
99. Verhanick, P.J. and C.C. Seamon. Research Methods for Undergraduate Students in Nursing . USA: Prentice-Hall, 1978.
100. Wagner, G. "The Detection of Carcinogenic Effects in Man", J. Cancer Res. Clin. Oncol., 97 , 215-221, 1980.
101. Westin, Alan F. Privacy and Freedom . New York: Atheneum, 1967.
102. Westin, Alan F. Computers, Health Records and Citizen Rights . Monograph 157, U.S. National Bureau of Standards, Department of Commerce. Washington, D.C., 1976.
103. Westin, Alan F. Computers, Personnel Administration and Citizen Rights. U.S. National Bureau of Standards, Department of Commerce. Washington, D.C., 1979.
104. Wynder, E.L. and G.B. Gori. "Contribution of the Environment to Cancer Incidence: An Epidemiological Exercise", (U.S.) JNCI, 58 (4), 825-832, 1977. Younger Report. Great Britain: Report of the Committee on Privacy . HMSO, Cmnd. 5012, 1972B.

## APPENDIX A - EPIDEMIOLOGY: DEFINITIONS, HISTORY, METHODS AND CRITIQUE

### A. Definitions

Epidemiology is the study of the distribution and determinants of disease frequency in human populations.<sup>1</sup> This oft-quoted definition stands as the most concise statement of the concern of epidemiology: human populations, as opposed to the clinical study of individuals; the distribution of health and disease, including sub-clinical disease identification; and identification of circumstances and factors associated with disease occurrence, whether they be microbiological, toxicological, genetic, social or environmental.

Epidemiology is identified by Holland and Karhausen, 1978, as one of the three basic tools of medical research. The first is clinical investigation of individuals, the second is experimental medicine using animal research, and the third is epidemiology, with its focus on the statistical analysis of disease patterns in populations. Clinical practice usually entails the intervention in the course of an illness either to prevent it becoming established or arrest it when established; Barker and Rose (1976) point out that epidemiology is related to prevention of disease in its attention to the early stages in the natural history and identification of pathogenic agents and environmental influences.

The comprehensive nature of epidemiological concerns has caused some debate as to whether epidemiology is best characterized as a method or as a science in its own right.<sup>2</sup> Fox et al., 1970, state that epidemiology "is not the proprietor of a well-defined and homogeneous body of knowledge as is the case with a basic or pure science....Rather, epidemiology is a discipline which has evolved relatively specialized methods for investigating disease causation and bringing to bear...specific knowledge and special skills from many other sciences." For example, tools used by the epidemiologist to take population samples, define and assess disease states, obtain personal histories, lifestyle information and psychological assessments, obtain environmental measures, review a variety of record systems, death and disease registries, do statistical analyses and interpret results are drawn from the fields of statistics, sociology, psychology, clinical medicine, biochemistry, toxicology, industrial hygiene, computer science and probably many more.

---

<sup>1</sup> This is a minor adaptation of the definition provided MacMahon and Pugh, 1970, which states: "Epidemiology is the study of the distribution and determinants of disease frequency in man."

<sup>2</sup> See Fox, Hall and Elveback, 1970, p.10; Anderson, 1965; and Terris, 1962.

More recent writers have stated fairly broad aims for epidemiology and appear to have sidestepped the debate over methodology or science. Lilienfeld and Lilienfeld (1980) refer to epidemiology as a "scientific discipline"; MacMahon and Pugh (1970) state "epidemiology is an applied discipline - that is, one concerned with the solution of practical problems". Both sources acknowledge broad purposes for epidemiology, from the elucidation of the etiology of disease to provision of guidance in the administration of health services, particularly preventive procedures and public health practices. Certainly all authors would agree with a statement by Wagner (1980) that "the strength of epidemiology lies in its capability of integrating data and findings from various sources into a biological concept."

The classical epidemiological triad of host, agent and environment, a model particularly useful for the understanding of communicable disease occurrence, must be modified to adapt to the applications of epidemiology to chronic diseases and the assessment of disease potential of agents, not yet associated with disease. Smith (1979) replaces the concept of agent with the concept of causative factors, thereby explicitly allowing for recognition of multiple causes. Host may be more usefully described as groups and their characteristics, and the environment has had its comprehensive ecological intent reaffirmed in its application to contemporary epidemiological problems. Barrett-Conner (1978) refers to this multifactoral etiology as the web of causation, an image that seems to express the nature of disease etiology and context of current epidemiological research more accurately than the more linear model of host, agent and environment. Anderson (1965) points out that where etiology is uncertain and the "agent" therefore undefined, or defined only very grossly, "host" and "environment" are really the only factors under study. He proposes the variables person, place and time as the focus of epidemiological study.

## B. History

The roots of epidemiology in public health go back to the mid-nineteenth century. Lilienfeld and Lilienfeld (1980) state that the hygienic or public health movement was a major stimulus to the development of epidemiology as a discipline. They describe the role of many of the early epidemiologists, notably W.A. Guy, William Farr, John Snow, William Budd, L.R. Villerme who were active in the public health and sanitary movements in Britain and France. The London Epidemiological Society, founded 6 March, 1850 stated among its purposes

- "1. to institute rigid examination into the causes and conditions which influence the origin, propagation, mitigation and prevention of epidemic diseases;

2. to institute original and comprehensive researches into the nature and laws of disease;
3. to communicate with government and legislature on matters connected with the prevention of epidemic diseases; " (Lilienfeld and Lilienfeld, 1980, 9(4), page 301.)

The lack of a public health movement and a vital statistics system in the USA during this same period hindered the development of epidemiology in the United States relative to Great Britain in the Lilienfelds' opinion. American students of the French teacher of quantitative reasoning in the study of disease, P.C.-A. Louis, who had strongly influenced many of the British epidemiologists, returned to the USA and established epidemiological centres in Boston and New York City. Without the impetus of a public health movement however, epidemiological activity did not flourish to the degree that it did in Britain.

Epidemiology is still seen by most writers as located in the public health sphere: "Epidemiology is a basic science of social medicine and public health" (Anderson, 1965); "as part of [epidemiological] method, the identification of populations at risk (emphasis in original) is an early step....Another part of the epidemiological model is ... prevention." (Smith, 1979); and "The science of epidemiology is concerned with cause, natural history and interrelationships of disease. It could be regarded as the analytic arm of public health and preventive medicine" (Corwin, 1949 in LeRiche et al., 1971).

However, some writers express a concern for a weakening relationship between epidemiological research and public health practice, related to increasing specialization of the former: "those who produce data needed for preventive programs (namely epidemiologists) and those in charge of carrying out such programs very often are not, unlike in the good old days, the same people at all,...[and] the increasing tendency toward overspecialization [has] ... contributed to making the liason between research and practice more tenuous." (Szklo, 1981). Other authors state "During the past ten years or so in the United States... the scientific discipline of epidemiology, with all its accomplishments, is increasingly becoming divorced from the public health activities of the real world" causing them to urge a renewed effort by epidemiologists to "maintain close contact with the problems of the real world" (Lilienfeld and Lilienfeld, 1980).

An illustration of how epidemiologists currently become involved in public health issues wittingly or unwittingly and how their perception of their work, as research or as a public health activity, is important is given by Stebbings (1981). He states that epidemiologists may be pulled from their various institutional locations, for example, local government health



departments, universities who play a service role within their region, or national governmental agencies, to evaluate the health impact of a local source of pollution. Such a task he refers to as health surveillance, an activity frequently initiated as a result of local public concern. He notes that these type of investigations frequently may not qualify as research per se since exposed populations are small, or pollutant exposure may be difficult to measure. The results are grossly undiscerning studies. Nevertheless, he argues that

"morally the public health practitioner may have stronger incentive than the researcher to be rigorous about methodology. Truth in research is usually arrived at through consistency of results from several teams of investigators; but truth in surveillance must be concluded from study of one limited population, usually too small. False positive results have undesirable effects on residents' morale, often on the economies of the local community, and in litigation. False negative results are unjust to the afflicted.

"The responsibility is heavy, but I'm not sure how we are best assured of rigorous studies..."

The public health practitioner may be more highly motivated to do rigorous studies of local problems, as Stebbings suggest, but conversely, may temper his/her results due to the very concerns Stebbings notes above: concern for economic impact on the community, residents' morale, possible litigation. The public health practitioner makes a decision about whether action is warranted, given the results of epidemiological study. Szklo (1981) states two factors influencing this decision: i) is the causal agent/suspected risk factor a necessity? how essential is its use or exposure level? ii) what are the size of benefits from its use in relation to the size of costs of modifying or substituting for it? Given that these are legitimate concerns of the public health practitioner, the question arises: to what extent do these concerns influence the areas of investigation undertaken, the rigor with which the investigation is done or the way in which results are communicated? This area of concern will not be addressed further, but is introduced here to give an appreciation in this overview of epidemiology of the social nature of epidemiological research.

There is no doubt that the early focussing of epidemiology on infectious diseases has shifted, as has public health practice itself, to include many other pressing health concerns. Anderson (1965) dates this broadening of perspective from Doll and Hill's (1950) work on smoking and lung cancer, and calls this a return to the style of nineteenth century epidemiology and its attention to the interrelationship of the individual and

the environment.

### C. General Types of Epidemiological Investigation

There are three major types of epidemiological investigation: descriptive, analytic, and experimental.

Descriptive studies are usually an initial attempt to create a profile of a disease or a population. Descriptive studies involve a rigorous attempt to state, using data from existing information and records, what disease precisely is being investigated; where it occurs and differences in rates (morbidity, mortality) among various locations; when it occurs, noting trends over years, seasons, or even the day; and who it affects, clarifying factors such as race, sex, age, socio-economic status, occupation group, behaviors (e.g. smoking, exercise) and medical events (e.g. pregnancy). This descriptive stage of epidemiological work is usually hypothesis generating.

Analytic studies go beyond the description of group characteristics and attempt to determine why the disease occurs. Analytic studies test the strength of associations between variables e.g. between presence of disease and history of particular exposures. This is still done within the realm of "natural experiments", that is, without manipulating the population under study. Both analytic studies and descriptive studies often rely on existing data, usually collected for purposes other than epidemiological research. These may be hospital or other medical or social service agency records, government held data collected through the census, vital statistics, income tax, or other programs, or they may be private records, such as employer personnel files or union membership lists. Analytic studies frequently may supplement these kinds of records with additional information collected solely for the research in question. Such supplementary information may be gathered through written questionnaires or verbal interviews, medical examination or testing, or environmental monitoring.

Analytic studies fall generally into two types, differentiated on the basis of the direction of the investigation. One kind of research design begins by identifying a population on the basis of an exposure of concern (as specific as a particular chemical or as general as a kind of industry or geographical region of residence) and then investigates all subjects for subsequent health status outcomes (often measured by specific kinds of morbidity or causes of mortality). The direction of investigation is from exposure to outcome.

The other type of design reverses the direction of investigation. A population is identified on the basis of a disease, medical condition or cause of death (an outcome), and individual histories of exposure are investigated.

The language used to describe each of these designs has varied over time and schools. To date there is no standard use of terms, which causes some difficulty. The terms retrospective and prospective are the source of much of the confusion. These terms have been used in two different ways (Friedman, 1974). One meaning relates solely to the time period over which the data were recorded in relation to the time the decision was made to do the study. In this sense, "retrospective studies involve observations that have been recorded in the past.... Prospective studies involve the collection of observations after the decision is made to carry out the study." (Friedman, 1974) Within this framework, either type of analytic study could be done in a retrospective or prospective manner.

A slight twist on this meaning of retrospective and prospective is MacMahon and Pugh's (1970) use. The terms refer, in their usage, to the investigators' relationship to the relevant events (cause(s) and effect(s)), rather than to the recording of those events as in Friedman's useage. MacMahon and Pugh state that in a retrospective study both the cause (exposure) and the effect (outcome) have occurred when the study is initiated. Either kind of analytic study can be retrospective. In a prospective study, relevant causes (exposures) may or may not have occurred and the investigator must wait for the condition, disease or death to occur to the members of the population under study. Obviously the type of analytic study which begins by identifying a population on the basis of an outcome cannot be carried out prospectively, within MacMahon and Pugh's use of the term.

The other use of the terms prospective and retrospective, as outlined by Friedman (1974), is related to the time sequence of investigation of causes (exposures) and the occurrence of disease. Fox et al. (1970) describe retrospective studies as looking backward (i.e. investigating) from the disease to prior exposure and prospective studies as looking forward from exposures to resulting disease. They state "the terms retrospective and prospective refer to how the data are analyzed and not to how or when they are collected."

A number of other terms have come to be used to refer to these different types of analytic investigations. The various terms and some of the authors who use them are listed below.

exposure ---> outcome

prospective (Fox et al., 1970)  
cohort (MacMahon and Pugh,  
1970; Friedman, 1974;  
Schottenfeld and  
Haas, 1978)  
incidence (Friedman, 1974)  
longitudinal (Schottenfeld  
and Haas, 1978)

outcome ---> exposure	retrospective (Fox et al., 1970) case-history (MacMahon et al., 1960; Schottenfeld and Haas, 1978) case control (MacMahon and Pugh, 1970; Friedman, 1974; Schottenfeld and Haas, 1978)
-----------------------	---

Cohort and case control are the terms most widely used at the moment<sup>1</sup>, permitting the terms prospective and retrospective to be used to refer to the investigator's relationship to events (following MacMahon and Pugh, 1970).

Following this usage, case control studies, involving as they do populations identified on the basis of the disease or condition of interest, are necessarily retrospective. The investigator is inquiring into exposures that have already taken place. Therefore the terms prospective and retrospective are used only in reference to cohort studies. If both exposures and outcomes have occurred at the time of the investigation, the study is described as retrospective; a study is prospective if the outcome has yet to occur. In some prospective studies both the exposure and the outcome have yet to occur.

Both Friedman (1974) and MacMahon and Pugh (1970) specifically state a preference for the terms prospective and retrospective to be used in the manner described immediately above, and that they be abandoned as synonyms for cohort and case control. The reason for this preference is the fact that in everyday use the terms bear a relationship to calendar time. The use MacMahon and Pugh propose corresponds with the everyday understanding of the relationship of the observer to events; either he/she is studying something that has already occurred (a retrospective study) or something that has yet to occur (a prospective study). The use of the terms independent of the observer's relation to events in calendar time is, in their view, confusing.

This use is not universal however and any mixture of terms can be found in reporting. Attempts to bridge the various schools sometimes results in terms like "historico-prospective

---

<sup>1</sup> Fox et al., 1970, refer to "case history" and "cohort" as new terms employed first by MacMahon et al. in 1960 to avoid the confusion arising from the everyday meaning of retrospective and prospective and the specific manner used by epidemiologists. They state "we have retained the old terminology, but readers should know that these synonyms exist and are being used with increasing frequency."

cohort study". The more successful avoidance of the use of prospective and retrospective is the term "historical cohort study" instead of MacMahon and Pugh's "retrospective cohort study".

Some other terms that are in use are longitudinal studies, prevalence studies and cross-sectional studies. Most case control and cohort studies are longitudinal; information on the population under study relates to more than one point in time. Cross-sectional studies collect cause and effect information for the same point in time; they assess current health status in relation to current exposures. Where disease in a population is determined in a cross-sectional manner, it will reflect disease prevalence as opposed to incidence. MacMahon and Pugh (1970) give an example of the use of these terms: "A study of the prevalence of respiratory disease in workers in a flax mill would be an instance of the cross-sectional approach in a study using the cohort method of study group selection".

The strengths and weaknesses of case control and cohort studies are to a large extent complementary. The case control study is particularly useful in studying rare diseases, in exploring in a detailed way or for multiple factors the backgrounds of affected and unaffected people and for the initial investigation of a specific etiological hypothesis (Schottenfeld and Haas, 1978; MacMahon and Pugh, 1970). They are usually cheaper and quicker than cohort studies. Their limitation is that information related to the hypothesized cause must be kept in either written records or memory until after the disease occurs. Often there may not be written records and memory may be biased by the fact of having developed the disease. This will make comparison with the non-diseased (control) group difficult.

Cohort studies are recognized as the "cadillac" of analytic investigations, particularly if they are prospective. This is primarily because they permit a direct measure of incidence or risk of developing a disease in individuals with a specific characteristic (Schottenfeld and Haas, 1978). Cohort studies are only appropriate when the disease in question is relatively frequent; very large cohorts would be required to obtain firm estimates of disease rates for rare diseases, which is an uneconomical approach (MacMahon and Pugh, 1970).

#### D. Epidemiology: Its Conceptual Framework and a Critique

Epidemiology, as a branch of medicine generally, has traditionally functioned from the same conceptual framework, or paradigm, as has clinical medicine. Within epidemiology particularly there has been little attention paid to the theoretical assumptions behind the practice. Paterson (1981) points out that in the teaching of epidemiology, the theoretical basis is usually implicit, and emphasis is given to methodology

and statistical technique.

Mishler (1981) notes that clinical medicine, pathology and biostatistics are referred to as particularly pertinent disciplines for epidemiology by MacMahon and Pugh (1970), while the social and behavioral sciences, which have to a much greater extent defined alternative conceptual frameworks within their disciplines, are omitted.

Both Mishler (1981) and Paterson (1981) argue that the lack of discussion within epidemiology of its theoretical basis implies a non-critical stance toward the paradigm which is in place. Paterson states:

If we are to accept with Lilienfeld<sup>1</sup> that the role of the epidemiologist is to 'integrate the data necessary for his analysis from diverse disciplines' including that from social science then it is important that we have a clear understanding of the theoretical principles being used by these disciplines and their relationship to the principles being used by the epidemiologist.

Mishler (1981) describes the conceptual framework as the biomedical model of illness. Paterson (1981) and Chalmers (1982) describe it as a positivist theoretical approach.

Mishler (1981) states there are four assumptions inherent in the biomedical model:

- i. the definition of disease as deviation from normal biological functioning;
- ii. the doctrine of specific etiology (i.e. that each disease has a specific pathogenesis and pathology);
- iii. the assumption of generic diseases (i.e. "that each disease has specific and distinguishing features that are universal to the human species. That is, disease symptoms and processes are expected to be the same in different historical periods and in different cultures and societies.")
- iv. the scientific neutrality of medicine (i.e. that medicine "has adopted not only the rationality of the scientific method but the concomitant values of the scientist, namely, objectivity and

---

<sup>1</sup> Lilienfeld, A.M. Foundations of Epidemiology, Oxford University Press, 1970. p.34.

neutrality. ... the implication [is] that the work ... is guided primarily by 'objective' scientific rules and criteria and therefore is relatively unaffected by wider social, cultural, and political forces." (quotations from Mishler, 1981)

Epidemiology relies upon this conceptual framework for definition of its problems, design of studies and interpretation of findings according to Mishler. As a result, even though epidemiology's investigation of the health of populations and communities contrasts with clinical medicine's focus on individual patients and cure of specific diseases, epidemiology is severely limited in its handling of social and cultural factors. They are used "essentially as indicators of situations that increase or decrease biological risk factors" (Mishler, 1981). Although epidemiology's "search for social correlates of illness falls outside the boundaries, or at least stretches the limits of the biomedical model", as Mishler states, "epidemiology does not offer an alternative to the biomedical model either in its definition of illness or in its theory of disease causation."

Paterson (1981) and Chalmers (1982), by locating epidemiology in the positivist tradition, argue, to the same end as Mishler (1981), that epidemiology has been limited as a result to a narrow description of disease causation. The positivist approach is characterized by Paterson and Chalmers as relying upon the careful examination of observable data (i.e. accessible to the senses); in medicine this involves the definition of disease as a "biological phenomenon caused by one or more factors which are always associated and observed in the existence of that disease" (Paterson, 1981). Paterson states that an effect of this is the machine or mechanical model of human functioning which is reflected in the nature of medical specialities, a division of labour based upon body parts and functions (e.g. cardiology, neurology, etc.). Paterson (1981) argues that this emphasizes objective rather than subjective criteria in the definition of disease and limits the ability to see disease as part of an organically integrated whole.

Chalmers (1982) states that positivism as employed in contemporary social sciences is conservative. This is primarily because observational foundations for theory development are dependent to a significant extent on the well-established theories of the day. He states "the positivist method leaves no scope for breaking out of the theoretical framework implicit in the observational data. Radically novel 'data' become available only when there is a radically new theory capable of guiding us to them".

Both Paterson (1981) and Chalmers (1982) argue that the positivist approach can lead only to "superficial" findings, that is, can describe, but cannot finally explain the phenomenon

under investigation. The structural relationship of factors associated with disease (including disease definition itself) is not investigated as a causal factor, i.e. as an underlying cause. For example, social class is not pursued as a potential cause of disease in and of itself. Instead, as Mishler has noted, when social and cultural factors are included as variables in epidemiological investigation they are used to locate specific populations at risk or to isolate certain disease-producing conditions, which then permits more direct tests of biologically grounded etiological hypotheses. The inability to examine social phenomena, the nature of society, the structure or form of society, means that epidemiology generally operates to preserve the existing social order. Change is approached from a functionalist or social engineering stance, by providing "practical solutions to practical problems within the framework of society as it is." (Paterson, 1981)

What alternative frameworks are offered for epidemiological theory and practice?

Mishler (1981) offers the most developed alternative, drawing upon the experience of social scientists. He offers "constructivism" or "social constructivism" as an alternative model. He describes this theoretical framework as a major tradition of sociological thought, proposing that "reality is constructed through human action, and does not exist independently of it. ... the world as a meaningful (emphasis in original) reality is constructed through human interpretive activity."

The significance of this approach for epidemiological investigation is stated by Mishler as follows:

... The work of physicians and other health professionals is understood as integral to the definition and diagnosis of disease, and hence in its production. ... their beliefs and practices with regard to diagnosis and treatment are topics of inquiry and require further analysis and interpretation. Therefore, the focus of investigation shifts from patients' symptoms as criteria for the diagnosis ... to the ways in which such criteria are applied, to institutional factors that affect clinical practice ... and to broader socio-cultural forces and values that influence the choice and use of particular criteria." (Mishler, 1981. p. 163)

Mishler gives as an example of the contrasting analytic



frameworks the work of J.R. Mercer<sup>1</sup> on the mentally retarded. She explicitly contrasts 'clinical' and 'social-system' approaches (parallel to Mishler's biomedical and constructivist models) to the definition and diagnosis of mental retardation. The clinical/biomedical approach describes mental retardation as a type of intellectual deficit which can be defined and diagnosed with respect to medical-pathological and/or statistical models of normality. Particular tests of intelligence are used to measure and diagnose what is assumed to be a personal characteristic; the pathology is in the person.

The social-system/constructivist approach, in contrast, approaches mental retardation as a social role that comes to be assigned to individuals through a complex sorting and selecting process. Mishler states that "In this perspective there is no one 'true' incidence or prevalence rate, and retardation is culture-specific."

Mishler reports that Mercer's study begins with the empirical association between ethnicity and mental retardation; in the public school system in California where her research was conducted, black and Mexican-American children were heavily over-represented in the population of mental retardates. Mercer and Mishler both argue that epidemiological research carried out in the clinical/biomedical tradition would stop at these findings, that is, determining that these are two populations "at risk". Theories accounting for higher rates of pathology might be generated, possibly proposing genetic differences, or environmental differences such as nutritional deficiencies, or sociological differences such as fatherless families.

Mercer, pursuing a social-systems/constructivist approach, investigated the question of sorting-selecting mechanisms. She determined that ethnicity plays a significant role in the labeling decisions made. For example, she reports that among all children who 'fail' the IQ test only 49 percent of Anglo children are recommended for placement in a special class (i.e. labeled mentally retarded) where 70 percent of Mexican-American and black children are recommended. She reports that average IQ scores do not differ among the three failing groups. Of those recommended for placement, only two-thirds of Anglo children are actually moved to the special classes while "nearly all" of the Mexican-American and black children are moved. Mercer's conclusion then is that "Anglocentrism" is in and of itself an explanatory factor in understanding the prevalence and incidence of mental retardation. Such a finding does not meet the criteria as an explanatory variable in the clinical/biomedical tradition.

---

<sup>1</sup> Mercer, J.R. Labeling the Mentally Retarded . Berkeley: University of California Press, 1973.

Chalmers (1982) limits his discussion of alternatives to positivism in epidemiology to a call for a scientific revolution (in a Kuhnian sense, that is a significant shift in the dominant paradigm, or conceptual framework.<sup>1</sup>). Chalmers proposes that such a revolution might be to shift from the concept of individualism (i.e. individuals as free agents, choosing lifestyles, making decisions about social institutions, etc.) which "permeates the modern conception of the social world" to a concept of class as a level of analysis in epidemiology.

Paterson (1981) proposes a "materialist epidemiology" which, like Mishler's constructivism, is "based on the view that social reality is the outcome of human action" (Paterson, 1981). He states that, like positivism, materialism proceeds from objective criteria but, unlike positivism, considers social forms as an objective reality, and therefore as facts or data with explanatory power. He states that "the aim of a materialist epidemiology would not be to deny the observed relationships between various diseases and different facets of the 'host', 'agent' and 'environment' but rather to penetrate beneath the surface appearances described in statistical associations to the underlying socio-economic and historical context in which these associations are located."

Applying Paterson's model to the study by Mercer of mental retardation described briefly above, we can presume that the historical and socio-economic factors giving rise to the Anglocentrism Mercer establishes as a significant factor would be relevant to the epidemiological determination of causation. Paterson quotes Navarro<sup>2</sup> in contrasting the positivist conception of causality, focussing on the microcausality of disease, with a materialist conception, which would take account also of the macrocausality, meaning the "political, economic and ideological power relations" of the society.

The implications of traditional epidemiology's reliance upon a positivist definition of disease (described by Mishler as the biomedical model) are best described by Mishler. The social contexts of patients and their illnesses have been neglected, with the result that social meanings of illness go unaddressed by the biological sciences. This in turn results in a limitation in both the understanding and treatment of disease by medical practitioners.

Mishler points out that there is a functional integration between the theoretical framework of medicine (the biomedical model) and its social organization. Emphasis on technical

<sup>1</sup> See Kuhn, T.S. The Structure of Scientific Revolutions, Chicago: University of Chicago Press, 1970.

<sup>2</sup> Navarro, Vincente. "Work, Ideology and Science: The Case of Medicine", *Social Science and Medicine*, 140, 1980.

expertise and bioscientific knowledge, and control over this knowledge, gives medical practitioners (and epidemiologists) authority to define themselves as the experts. This is reinforced through hierarchical relationships among different types of health-care personnel and between physicians and patients (or researchers and the population under investigation), which in turn supports the monopolistic control over matters of health by physicians as a profession in the society.

Mishler argues that an alternative framework would see medical practitioners (and following from this, researchers) as one kind of participant in the social construction of disease. He states:

... medicine, although viewed as an applied technology within the biomedical framework of assumptions about illness as generic and universal, may more adequately be understood as a social practice. That is, ..., medicine is active interpretive work through which a particular social reality is constructed, a 'reality' constituted by diagnosed illnesses and prescribed treatments. ... [this does not involve] only the application of standardized biomedical criteria and procedures ... [but is] guided by sociocultural values and assumptions, organized and regulated by social norms and institutional requirements, and socially consequential in its effects on the rights and responsibilities of those labeled as sick ... (Mishler, 1981, p. 162)

In summary, Mishler argues that when illness is seen as socially produced, a wider range of information and interests must be taken into account than is required by the biomedical model. He states that although this can be seen as a threat to medical authority and the status and power that are the accompaniments of medical dominance, it also implies that patients and others are potential allies of physicians in affecting the the process of labeling, diagnosis, management and treatment of illness and therefore in providing more humane and socially responsive care. He suggests that clinical practice could be returned to its social context, turning away from the medicalization of life and towards the resocialization of medicine.

## APPENDIX B - OCCUPATIONAL INJURY AND DISEASE: DIMENSIONS OF THE PROBLEM

Occupational health research is an area of increasing public interest because of growing concern about the rates of injury and disease attributable to the workplace. Aykroyd (1980) states "Over the last eighteen months, workplace hazards have continued to be a major focus for public interest, government policy and labour relations...Growing recognition of the extent and costs of on-the-job illness and injury has been a major factor in stimulating public and government concern." Similarly, Reschenthaler (1979) notes increasing interest in the area in the 1970s and lists the following reports as an indication of increased attention to the area:

- report of the Royal Commission on the Health and Safety of Workers in Mines in Ontario, 1976 (the Ham Commission);
- the Beaudry Commission in Quebec (Comite d'etude sur la salubrite dans l'industrie de l'amiante) (1976);
- Robens Report on Health and Safety at Work (1972) in Britain;
- the Report of the Industrial Health and Safety Commission (Gale Commission) (1975) in Alberta;
- the major U.S. programs introduced in 1970: the Occupational Safety and Health Act (OSHA) and the National Institute for Occupational Safety and Health (NIOSH).

Some data is presented here to sketch the dimensions of the occupational health and safety problem.

Ashford (1976) reports a twenty-nine per cent increase in the reported injury rate in industry in the USA between 1961 and 1970. He cites US National Safety Council estimates of 14,200 fatalities annually due to accidents on the job and 2.3 million disabling injuries annually. These statistics refer to non-agricultural workers only. Canadian data reported by Manga et al. (1981) state that more than 1 million cases of occupational disease, injury or fatality are reported annually to Canadian workers' compensation boards. Manga et al. (1981) cite a Labour Canada report of 1979 showing an average of 12.5 reported injuries per 100 workers each year between 1969 and 1978. It should be noted that it is estimated 20-30% of the Canadian workforce are not covered by workers' compensation schemes (Manga et al., 1981) and that British (Great Britain, 1972A) and American (Sands, 1968) studies found an underreporting of injuries by 25% and 50% respectively. Ashford (1976) cites a report (Gordon et al., 1971) done for the US Bureau of Labour Statistics which found a ratio of serious but unreported injuries to reported disabling injuries of ten to one.

The ratio of disabling to non-disabling injuries showed a

pronounced increase in Canada from 1969 to 1978 (.576 in 1969 to .846 in 1978; Manga et al. 1981) though Manga et al. (1981) caution that this may reflect an increase in underreporting of non-disabling injuries rather than a relative increase in disabling injuries. Underreporting of non-disabling injuries might result from a changing social and economic climate where unemployment is increasing, and job security decreasing. A slight decline in injury rates from 1973 to 1979 also may be a function of social factors, according to Manga et al. (1981). Rates are influenced by the changing profile of employment opportunities in Canada, with growth in recent years taking place primarily in relatively safe sectors such as finance and service jobs rather than in the more hazardous area of forestry, mining and manufacturing. In addition, in times of high unemployment, young inexperienced workers are the first to be laid off. Since this group experiences higher rates of occupational accidents, their departure from the labour force is likely to lower injury rates.

Annual occupational fatalities have averaged 13.4 per 100,000 workers in Canada between 1967 and 1977. Mining and forestry report averages of 126.9 and 113.5 per 100,000 respectively, with fishing reporting 81.8. Construction and transport workers follow with 38.8 and 28.2 deaths per 100,000.

Compensation costs which include medical aid, compensation for lost wages, and pensions totalled nearly one billion dollars in Canada in 1978. Employers absorb additional costs over and above their workers compensation contributions, in the form of work disruption, costs of hiring and training a substitute worker, damage to equipment and materials, drop in worker morale, and possible legal fees. Ashford (1976) cites US National Safety Council estimates of direct costs to employers of occupational illness and injury as about one per cent of the US gross national product - about 10 billion dollars per year in 1976.

The worker and the worker's family also incur costs including loss of full pay, loss of self esteem, costs of physical pain and psychological suffering. Injuries often increase stress in families, sometimes to the extent of precipitating marital and family breakdown. These events often result in new social welfare costs for society at large. These costs which fall outside the firm's profit and loss statements are referred to by economists as "externalities" and the effect of this externalizing of costs is a reduced incentive for firms to improve health and safety standards and practices (Manga et al. 1981).

Occupational disease is a small proportion of claims handled by workers' compensation systems. Ashford (1976) cites US Bureau of Labour Statistics figures for 1971-2 which report occupational illness as less than five per cent of reported injuries and illnesses. One-third of those illnesses recorded

were occupational dermatitis cases.

In Canada, a review of workers' compensation claims from three provinces by Ison (1978) demonstrated only two to seventeen per cent of fatal claims allowed were for disease. Of permanent disability awards, 3.4 to 11.3 per cent were for disease; the majority of these were for hearing loss. When hearing loss claims are excluded, only 0.8 to 1.7 per cent of permanent awards in 1976 from the three compensation boards investigated (Alberta, Manitoba and British Columbia) were for disease. This low proportion of compensated occupational disease cases can be compared to the high proportion of premature <sup>1</sup> disability from disease cases handled by the Canada Pension Plan disability pensions : 95.2 per cent are for disabilities resulting from disease; only 4.8 per cent are for disabilities resulting from trauma (Statistics Canada, 1974. <sup>2</sup> in Ison, 1978). Ison comments

"... while the bulk of permanent disabilities and premature deaths result from disease, the bulk of workers' compensation claims for death and premature disablement result from trauma. There is no obvious explanation for this contrast.

"It is possible that disablement from disease is several times that which would be indicated by compensation data."

Ashford (1976) cites a NIOSH- sponsored study <sup>3</sup> carried out by the University of Washington on the prevalence of occupational ill-health. Nine hundred and eight workers were medically assessed and over 1100 medical conditions were identified. Of these, thirty-one per cent were identified as of occupational origin, and an additional ten per cent described as having a suggestive history of occupational origin. The incidence of occupational disease was determined to be 28.4 per 100 workers. Only three per cent of the conditions identified were located in workers' compensation records. Skin diseases accounted for only eighteen per cent of conditions identified, though as stated above, the US Bureau of Labour Statistics reports skin diseases as one-third of all occupational illnesses reported. Hearing loss accounted for twenty-eight per cent of the conditions identified which compares with over half of the disease claims allowed by the three workers' compensation boards

<sup>1</sup> Premature refers to people aged twenty to sixty years.

<sup>2</sup> Statistics Canada. Causes of Death, Ottawa, 1974.

<sup>3</sup> Discher D.P., et al. Pilot Study for Development of an Occupational Disease Surveillance Method, (US) HEW publication number (NIOSH) 75-162, 1975.

investigated by Ison (1978) and referred to above.

There are a number of fairly obvious factors which make it likely that occupational diseases are under-recognized in the compensation system. Injuries are usually

- i) definite in time and place,
- ii) have a definable etiology and
- iii) as a result, generally impose more or less immediate consequences on the worker, the employer, and the insurance carrier (adapted from Manga et al. 1981).

In contrast, occupational diseases usually have latency periods of five to forty years and often have etiologies which are complex and/or not well-understood by the medical profession, the worker or the employer. They may be the result of an interaction of environmental, lifestyle and occupational hazards. These factors, along with high workforce mobility, limited records of chemicals in use in production processes and limited knowledge by the worker of what materials he/she is working with, result in a much lower likelihood of assignment of responsibility for an occupational disease to a workplace exposure by the worker or his/her physician, and therefore a much lower likelihood of an accounting of industrial disease in the compensation system.

## APPENDIX C - OCCUPATIONAL HEALTH AND SAFETY - ECONOMIC THEORY

In a perfectly competitive market model, usually the normative model in economic studies, it is assumed that:

- firms maximize profits (and therefore minimize costs);
- individuals maximize utility (measured by real income);
- both workers and firms are fully informed about health and safety hazards;
- information is costless to obtain and process;
- all costs are internalized (i.e. no costs generated by private enterprise are absorbed by any individual or institution other than the enterprise itself);
- there is perfect labour mobility and full employment;
- firms and workers are price takers.

(adapted from Manga et al., 1981 and Reschenthaler, 1979)

Within this model, it can be predicted that a rational worker will only work at employment which compensates adequately for any risk differential involved in the work. Firms will find it necessary to offer wage premiums which compensate for expected losses or the cost of insurance against expected losses. Reciprocally, improvements in working conditions which reduce hazards would meet with agreement by workers to reduce wage premiums to reflect new hazard levels. Equilibrium would be reached where the marginal cost of reducing hazard in the industry equals the marginal savings from such a reduction. In the model, all costs of occupational hazards would be recognized as part of production costs and hence be passed on to consumers in prices, therefore adding to the price of products which are hazardous to produce. Higher prices for goods more hazardous to produce would reduce demand.

Manga et al. (1981) review the empirical data on the extent to which compensating wage differentials exist for hazardous work. Generally, a positive relationship between wage rate and some measure of hazard (variously measured by fatality rates, injury rates, severity rates, workers' perception of hazard) is observed, although some studies have found a negative relationship or a different relationship depending upon the race of the worker (positive for non-white males, no significant differential for white males). One study cited by Manga et al. (1981) shows an increase in risk premium in "very risky" occupations when unions were present.

However, Manga et al. (1981) point out that problems exist not only with the different measures of hazard used but also with the reliability and accuracy of data on injury and disease rates. Other problems with these studies are also mentioned. The conclusion reached by Manga et al. (1981) is that risk premiums do exist, but that the market is "far from perfect. That is, the market does not generate sufficient risk premiums to achieve socially optimal levels of work injuries" (page 74). They also state that even people who strongly support a market



paradigm solution to the reduction of occupational injury concede that the market paradigm is less valid for generating socially optimal levels of occupational disease.

This situation is known as "market failure". There is an underinvestment by firms in occupational health and safety. A number of factors are involved, among them the fact that the economy does not normally experience full employment, and labour mobility is not as fluid as is necessary for the market paradigm to work efficiently. These factors separately and together increase the vulnerability of some workers, causing them to accept wages which do not fully compensate for the risks assumed. Less safety is then provided due to these imperfections of the market.

Another major reason for market failure in the area of occupational health and safety is the failure of the perfect knowledge and full information assumption. Quantity and quality of information on industrial hazards, particularly those associated with occupational disease, is not perfect. Not only is there a lack of any information at all on many hazards (e.g. many chemicals individually and in combination used in production), controversy exists within the scientific and medical communities about what is known. Sophisticated research is required to assess many of these potential hazards; workers and firms for the most part cannot simply learn through experience. Where scientific information does exist, accessing it is also a major problem. It costs money to process, interpret and communicate information. Obviously big firms and big unions are in a better position to obtain and use information than small firms, small unions or individual workers. Even so, there are limited incentives for even big firms or unions to generate information. The costs are high and the nature of information is such that it is more of a public good than a private good (i.e. it is rarely saleable at a profitable rate; this refers to information about hazards, not patents for chemicals or safety equipment).

The information problem would be less severe as a cause of market failure if full compensation for injury or disease were available through the courts or the compensation system when it is not adequately built into wages (as we have seen it is not). The establishment of workers' compensation systems at the turn of the century was a result of the ineffectiveness of the courts to efficiently or adequately provide compensation and also now prohibits use of the courts for most industrial disease and injury claims. As a result, firms, either directly or indirectly through the workers' compensation systems, do not bear the full costs of occupational disease and injury. Instead, a good portion of the costs are borne by the affected worker and his or her family, and by society at large.

Attempts to estimate the size of the hidden costs have many problems. Some of the problems relate simply to lack of

information, not only about all indirect costs but also true rates of injury and disease. However, educated guesses of the hidden costs range from 3.5 to 5 times direct costs (Manga et al., 1981).

The other major factor related to market failure in occupational health and safety is known as the externalities factor. Hazards to the public at large generated by firms (e.g. air, water, noise pollution) result from underinvestment in pollution control. Real production costs would reflect the costs necessary to leave the environment and the public unharmed. Where the society either bears the effects of pollution or cleans up hazards in the environment originally generated by firms, the firm has successfully externalized a production cost, and the competitive market incentive to limit pollution is lost. Usually improved health and safety standards for workers result in reduced hazards for the public, and vice versa. Market failure from either of these points of view thus impacts upon the other party.

The result of market failure in this area is resource misallocation, since artificially lower costs of production will result in artificially low prices and resulting overproduction. In addition there is the fact that the costs, in the form of industrial injury and disease, are not shared equally by all consumers who benefit from lower product prices. This represents a transfer of real wealth from the victim of occupational injury and disease to the consumer. Although equity is ultimately a political concept, economics can be very useful in illuminating specifically who benefits and who pays as a result of present policies.

What is interesting to note in this brief neo-classical economic overview is that third party (i.e. governmental) intervention is necessary in this market in some form to overcome inherent problems of market failure (Economic Council of Canada, 1981). Forms of intervention could vary, addressing variously the informational inadequacies, the costs of processing information, or the externalization of some of the costs of disease and injury, for example.

However, the public discussion on these issues is characterized as a political one for the most part, rather than a solely rational one, and labour's demands for more adequate compensation of occupational injury and disease victims or a greater part for workers in design of regulations and monitoring of workplaces is generally perceived as a socialistic or left-leaning platform. In fact, such demands can be seen to emanate from a neo-classical competitive market model.

The realpolitik of the occupational health and safety arena results in government desiring to appear not to favor labour's proposals over employers', and therefore no significant change in the social organization of occupational health and safety

programs occur. Thus, serious market failure occurs, rather than rational policy formulation which might lead to significant alteration in resource allocation or distribution of costs and benefits from their current state.