

reevaluate them but these costs may not be felt by individuals or by prevention programs if third party payment systems take up costs of dealing with false positives. As Foltz and Kelsey have noted,⁵ professionals have an incentive to upgrade seriousness ratings in their evaluations of screening specimens in order to assure their patients of service. It is unlikely that such sources of variation in measurement of benefit and effectiveness will be rooted out by simple maneuvers because they involve complex behaviors in the response of providers and consumers to service and research situations and to options offered by features of health care programs. This implies that it is not only the mode of valuing illness costs (costs of unprevented events) that introduces measurement problems into important decisions about targets and means for health improvement.

The paper by Smart and his colleagues¹ on the incidence method also is concerned with the significant methodological issue of the conflict between the desire for a common denominator or numéraire for measurement of all types of losses and prudence about aggregating the incommensurable. The agreement of analysts to combine direct with indirect economic costs is only a convention and entails the problem that the sacrifices are made by different sectors of society. The treatment of non-economic costs remains a difficult matter. Asking people about the money value they would set on a year of life under certain conditions cannot be entirely adequate because of the tremendous variation of circumstances—including states of health and wealth—in which such values would be chosen, and of respondents' frame of reference about their responsibility for financing the program that would accomplish the good result.

It becomes more evident as the evaluation method literature develops that the complexity of the assumptions implies a negotiatory process in selecting health goals and programs. Methods of valuation reflect competition between age groups, types of professionals, and types of health care institutions, for a prior place in health budgets. Public servants and a variety of professions are affected by whether emphasis is placed on environment, life-style, or health care systems in modifying health states. Similarly, it is a bread-and-butter matter as well as a matter of professional justification and enhancement when decisions are made to attack specific diseases or go after risk and co-risk factors. The ar-

gument of the Office of Technology Assessment⁶ that non-quantifiable elements are given more adequate expression when all elements entering into a decision are arrayed is healthy because it makes the negotiatory process more explicit.

Observation of society shows that there is no one mode of valuing life or of comparing the social worth of a year in the lives of two different individuals. A pecuniary standard is adopted whenever reference to comparative productivity loss is used as a guide to health policy, and this is in tune with the workings of institutions in which money talks—i.e., markets. Yet this standard is biased by social discrimination factors influencing productivity and earnings of different race, age, and sex categories. In the settings in which caring acts occur, other standards of individual worth are used. The problem of applying distributive ethics to health care policy seems to call for improved distribution of productivity. Meanwhile claims of non-productive groups based on past services and desires of economically active groups for protection of their dependents set up numerous constituencies. We will have more adequate choices if we continue to be interested in better methods of recognizing various forms and impacts of losses and suffering due to illness, invasive treatments, and living with risks.

CHARLOTTE F. MULLER, PHD

REFERENCES

1. Smart CN, Thompson MS and Hartunian N: Incidence and costs of cancer, coronary heart disease, motor vehicle injuries, and stroke. *Am J of Public Health* 1980; 70:1249-1260.
2. Rice DP: Estimating the Cost of Illness (Health Economics Series No. 6), U.S. Public Health Service, Washington, DC, 1966.
3. Cooper BS and Rice DP: The economic cost of illness revisited. *Soc Sec Bull* 1976; 39:21-36.
4. Alderman MH: High blood pressure: Do we really know whom to treat and how? *Sounding Board, N Engl J Med* 1977; 296:753-754.
5. Foltz AM and Kelsey JL: The annual pap test: A dubious policy success. *Milbank Memorial Fund Quarterly*, 1978; 56:426-462.
6. U.S. Congress: The Implications of Cost-Effectiveness Analysis of Medical Technology. Congress of the United States, Office of Technology Assessment, Washington, DC, August 1980.

Record Linkage Systems—Canada vs the United States

Canada is well ahead of the United States in linking national data systems to monitor health and to facilitate large-scale epidemiologic studies of health hazards. The paper of Smith and Newcombe in this issue of the *Journal*¹ reveals the remarkable progress Canada is making in an area where US efforts are notably weak. The Canadian Mortality Data Base, a tape file of all 4 million deaths in Canada for the period 1950-1977, the National Cancer Incidence Reporting System (1969-, with 290,000 cancer reports in hand, and Ontario soon to close the gap in the list of provinces reporting), and a

10 per cent sample of the Canadian work force are powerful and economical tools for exploring genetic, environmental, life-style, and iatrogenic influences on health. Building on the pioneer work of Newcombe and his associates in record linkage by computer,² Statistics Canada has now begun to make available to medical investigators and health authorities automated facilities for follow-up studies without compromising personal privacy or confidentiality of individually identified records.

The announcement of the Canadian facilities comes at a

time when the US public, the Congress, health authorities, and medical investigators are increasingly concerned with the inadequacy of US resources for the detection of health hazards and the quantitative estimation of risks. These inadequacies apply especially to the detection of hazards of the work environment, to end points associated with long latent periods, and to measurement of risks from low levels of exposure to known toxic substances. The Canadian government has a central statistical agency—Statistics Canada—whereas in the US government statistical functions are scattered among many special-purpose agencies. Hence, Canada has a great advantage over the US in its capacity to link national data sets even under rigorous restrictions as to confidentiality of administrative records. Consider, for example, the data resources of the US Census Bureau, the Social Security Administration (SSA), the Health Care Financing Administration, and the National Center for Health Statistics, each with its own legal and administrative restrictions on access to its records—restrictions that impede linkage even when undertaken with research intent and for merely statistical presentation. Consider that each agency has its own mission that dictates its own data gathering program and even the accessibility of its data for other purposes, and that nowhere in the US government is there a locus of responsibility with funds for integrating independent data bases to serve broader national needs. Take, for example, the growing concern over the hazards of the work place. It is not served, as it deserves to be, by a system for creating, on a national scale, cause-specific mortality information on occupation and industry. At the time of the 1950 Census, an effort was made to establish a benchmark of this nature by combining death certificate information on industry and occupation with parallel Census data.³ The effort was only partially successful because of differences in definitions and recording practices, and because, in the absence of the quality control that regular use brings, death certificate information on occupation and industry is not of the highest quality. In the United Kingdom, however, there is a long tradition of decennial reports on occupational mortality based on this same combination of death certificate and census information.⁴

A 1973 American Public Health Association monograph based on manual matching of the April 1960 census long forms (a 25 per cent sample) with death certificates for the period May–August, 1960, documented important socioeconomic differentials in mortality and suggested that “biomedical knowledge already available is not effectively within the grasp of lower socioeconomic components of the population.”⁵ It was too small a sample of deaths, however, to have yielded information on differential mortality by occupation and industry.

Although the US Privacy Act of 1974, and perhaps even more the Tax Reform Act of 1976, greatly discouraged efforts to link individually identified records in the various data bases maintained by the federal agencies, there are a few encouraging developments. Most important is the creation of the National Death Index by the National Center for Health Statistics (NCHS).⁶ Suggested in 1968 by a subcommittee, chaired by Brian MacMahon, of the US National Committee

on Vital and Health Statistics,⁷ and beginning with 1979 deaths, the National Death Index is scheduled to become operational in 1981 under the dynamic leadership of Dorothy Rice, Director of NCHS.

In keeping with its new mandate^{8,9} to “develop a plan for collection and coordination of statistical and epidemiological data on the effects of the environment on health,” the National Center for Health Statistics is also planning a new data base on occupational mortality derived from information routinely entered on the death certificate. Long an integral part of the standard US certificate, but seldom coded by vital statistics registrars in the states, the usual occupation and industry of the deceased will be coded initially by a small group of states and, hopefully, by all states eventually. These data will enable investigators to study differential mortality by occupation and industry by means of proportional mortality ratios, as Milham has done in Washington State.¹⁰

Other efforts are being made to develop systematic national mortality data on occupation and other socioeconomic and demographic variables. Epidemiologists of the National Heart, Lung, and Blood Institute have proposed that a sample of about 4 million be drawn from the long form schedules of the 1980 Census, names coded and punched, and a file prepared for periodic collation with the National Death Index in subsequent years. This would provide information now unavailable on mortality differentials associated with the numerous socioeconomic and environmental variables on the Census long form. Multivariate analysis of such data could be useful in clarifying the relative importance of the work place vs life-style in creating such mortality differentials. A test of feasibility is to be conducted in 1981, based on matching a sample of the Current Population Survey to the Index. Another example is the proposal to add cause of death to the 1 per cent Continuous Work History Sample (CWHS) of the Social Security Administration,¹¹ under funds provided from outside the SSA as cause of death information does not further the SSA mission of income maintenance. This addition would provide differential, cause-specific mortality by industry for a representative sample of about 2 million in covered employment. The Social Security Administration lacks information on occupation and the CWHS may well be too small to provide reliable information on differential occupational mortality by cause. Nevertheless, it is a highly significant longitudinal sample with data from 1957 onward and conceivably might be augmented if occupation became available from another source, e.g., federal tax returns. It is unfortunate that the mission of SSA is so narrowly defined that it has no responsibility for providing mortality information on the US work force.

With a number of initiatives under way, the outlook for systematic national data on occupational mortality in the US is improving. And certainly the availability of the National Death Index will begin a new era for US epidemiologists interested in cohort studies.

The 1977 report of the Privacy Protection Commission¹² has encouraged a more balanced view of the competing interests of the individual and society in the creation of new

information from individually identified records. It now seems likely that the 1974 Privacy Act will be amended, as the Commission recommended, by legislation reflecting this balance and easing some of the restraints on scientific research. A hopeful sign of this in 1978-1979 was the drafting of an Administration bill entitled "Confidentiality of Federal Statistical Records" that would have established conditions for the inter-agency exchange of individually identified records for statistical purposes. If enacted, this "enclave" bill would have gone far to remove barriers among federal agencies and to facilitate the linkage of data sets in the interests of research in various fields, including health. Statistics Canada is already such an enclave.

GILBERT W. BEEBE, PHD

Address reprint requests to Gilbert W. Beebe, PhD, Clinical Epidemiology Branch, National Cancer Institute, Rm 5A21 Landow Bldg., Bethesda, MD 20205.

REFERENCES

1. Smith ME, Newcombe HB: Automated follow-up facilities in Canada for monitoring delayed health effects. *Am J Public Health* 1980; 70:1261-1268.
2. Newcombe HB: Record linking: The design of efficient systems for linking records into individual and family histories. *Am J Hum Genet* 1967; 19:335-359.
3. Guralnick L: Mortality by Occupation Level and Cause of Death among Men 20 to 64 Years of Age: United States, 1950. Washington, DC: Govt Printing Office, 1963. Vital Statistics—Special Reports, Vol. 53, No. 3.
4. Registrar General: Occupational Mortality, the Registrar General's Decennial Supplement for England and Wales, 1970-72. London: Her Majesty's Stationery Office, 1978. Series DS No. 1.
5. Kitagawa EM, Hauser PM: Differential Mortality in the United States: A Study in Socioeconomic Epidemiology. Cambridge, MA: Harvard University Press, 1973.
6. Patterson JE: The establishment of a National Death Index in the United States, IN: Cancer Incidence in Defined Populations, Banbury Report 4, Cairns J, Lyon JL, Skolnick M (eds). Cold Spring Harbor, NY: Cold Spring Harbor Laboratory, 1980, pp. 443-447.
7. National Center for Health Statistics: Use of Vital and Health Records in Epidemiologic Research, A Report of the United States National Committee on Vital and Health Statistics. Washington, DC: Govt Printing Office, DHEW pub. no. (HSM) 73-1265 (reprinted), 1973.
8. Health Services Research, Health Statistics, and Health Care Technology Act of 1978. 95th Congress: PL 95-623, Sec. 8.
9. National Center for Health Statistics: Environmental Health—A Plan for Collecting and Coordinating Statistical and Epidemiologic Data. DHEW pub. no. (PHS) 80-1248, Hyattsville, MD: NCHS, 1980.
10. Milham S Jr: Occupational Mortality in Washington State, 1950-1971. Washington, DC: Govt Printing Office, DHEW pub. no. (NIOSH) 76-175-A-C, 3 Vols, 1976.
11. US Department of Commerce, Bureau of Economic Analysis: Regional Workforce Characteristics and Migration Data: A Handbook on the Social Security Continuous Work History Sample and Its Application. Washington, DC: Govt Printing Office, 1977.
12. Privacy Protection Study Commission: Personal Privacy in an Information Society. Washington, DC: Govt Printing Office, 1977.

Death Index to be Established by NCHS

The National Center for Health Statistics NCHS is establishing a National Death Index to be used for statistical purposes in medical and health research. It is designed primarily to facilitate prospective studies to determine the relationships between chronic degenerative diseases, such as cancer, and environmental, occupational, medical, and lifestyle factors.

Through contractual agreement, the State vital statistics offices will provide the National Center for Health Statistics with computer tapes. These tapes, beginning with those deaths occurring in 1979, will include a standard minimum data set for each death and will be compiled into the National Death Index. The standard data set will include information necessary for indexing and searching purposes.

It will then be possible for NCHS to compare lists of individuals submitted by users of the Index with the national file and to indicate to the user any probable matches along with the appropriate State death certificate numbers and the names and addresses of the vital statistics offices of the States where the deaths occurred. The user will make the necessary arrangements with the State offices for the procurement of death records or for any specific statistical information such as cause of death.

The initial National Death Index will include deaths from 46 registration areas, which account for 94 per cent of deaths in the United States. Five of the remaining eight registration areas will join the system by reporting deaths occurring in 1980, bringing national coverage up to more than 98 per cent. The remaining three areas are expected to provide data for 1981.

A user's manual, which includes an application form, is being prepared for distribution in early 1981. Potential users who wish to receive the user's manual should contact Robert Bilgrad, Division of Vital Statistics, NCHS, Room 1-44, Center Building, 3700 East-West Highway, Hyattsville, MD 20782.