tool to anticipate intrinsic risk for unhealthy longevity just as it is now a tool to prevent certain diseases of early life. That is why the genetic screening program in New York City is such an interesting "experiment." It is generating knowledge and expertise which, when fully appreciated, will transcend its original impetus from HbS-associated disease.

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Long-Term Follow-Up Is a Problem

In this issue of the Journal, Nash, *et al,* report on the difficulties of conducting the national cooperative Diethylstilbestrol-Adenosis (DESAD) Project.[1] Their experience provides yet another example of the problems we face in conducting medical follow-up and epidemiologic studies in this country when many years intervene between exposure and disease. Despite the allocation of tremendous funds to medical care and the elegance of our technology, linking events in the life history of the individual in order to advance medical science is usually difficult and often impractical.

It is not only research on the late effects of drug therapies that suffers from the difficulties experienced in the DESAD Project. Unless they can be performed within closed medical care systems, or within population-based medical information systems, virtually all long-term follow-up studies are subject to some of the difficulties faced by the DESAD investigators, especially if events and outcomes other than mortality are at issue.

The barriers to long-term studies come to national attention only indirectly, as in the deliberations of the Privacy Protection Study Commission established by the Privacy Act of 1974.[2] The Commission was charged with surveying information systems from the standpoint of privacy and confidentiality and recommending to the President and the Congress changes in legislation designed to bring into better balance the information needs of society and the privacy of the individual. Perhaps the Congress recognized that the Privacy Act of 1974, having been hastily drafted in the wake of Watergate, might well be imperfect and need amendment. Although abuses arising from medical research seem not to have been any part of the driving force leading to their enactment, the Privacy Act and the later Tax Reform Act of 1976[3] have had a chilling effect on medical research both directly, in their restriction of access to federal record systems, and indirectly, through their ripple effects in state legislatures and private institutions.[4] The Commission took seriously its charge to balance public and private interest and, if enacted, its 1977 recommendations for modifications in the Act[5] would ameliorate many of the difficulties that beset the medical investigator. Unfortunately, the Privacy Act remains essentially unchanged even now, five years later.

The Tax Reform Act, on the other hand, has been modified to provide medical investigators with access to the taxpayers' address file of the Internal Revenue Service (IRS), but only through the National Institute for Occupational Safety and Health (NIOSH) ". . . for the purpose of locating individuals who are, or may have been, exposed to occupational hazards in order to determine the status of their health or to inform them of the possible need for medical care and treatment."[6] Later this "NIOSH window" was widened to admit individuals who may have been exposed to occupational hazards during active military service.[7] The wording of these amendments is quite restrictive, even for research on occupational hazards, and there remains an urgent need to modify the Internal Revenue Code further so that qualified medical investigators working under approved protocols may have access to the filing address and date of filing.

Two major sources of mortality information—the Social Security Administration (SSA) files and the Veterans Administration (VA) files—were greatly impaired by the 1981 tax bill that curtailed eligibility for the lump-sum death benefit programs of SSA, VA, and other agencies beginning October 1, 1981.[8] Had the National Death Index not been put in place by the National Center for Health Statistics (NCHS)[9] before that curtailment took place, we would have no truly national source of mortality follow-up after 1981.

In establishing the National Death Index, a single file of death information for the entire US population starting with 1979 deaths, NCHS took a major step to facilitate and improve follow-up studies targeted to deaths in 1979 and subsequent years, but it remains dependent for funding on other federal agencies and users of the Index. The usefulness of the Index would be markedly improved by extending its coverage retroactively by 10 or even five years. For deaths before 1979, the main sources of nationwide mortality follow-up remain the files of the SSA[10] and the VA.[11] The IRS file would be an excellent source of information on the living, who generally constitute the great majority of any cohort under study and whose current status is the more difficult to establish. As a last resort, there are the files of the individual states and other registration authorities; but these vary as to the period for which they are automated, and their multiplicity makes searches slow and expensive.

Often the research need is for information on morbidity, disability, or behavior rather than survival or death; thus, in the absence of an essentially closed medical care system, the investigator must have access to the individual subject in order to obtain responses to a questionnaire or an interview, or to perform some specific examination procedure. Although there are many approaches that can, and generally must, be used, their effectiveness depends on the completeness of the initial identifying information, residential stability, availability of funds, and dedication of the investigator. A judicious use of the IRS address file could completely transform the potential for follow-up studies with end-points other than mortality.

Kurland has been able to make very effective use of the unique medical record archive of the Mayo Clinic and ancillary records of the population of Olmsted County, Minnesota, to provide a population-based medical information system of great versatility and historical depth.[12] One medical care system of proven value for studies of drug-induced illness is the Group Health Cooperative of Puget Sound used by Jick, *et al,* in their study of replacement estrogens and endometrial cancer.[13] Of potential value is the Medicaid Management Information System (MMIS) established by the Health Care Financing Administration and many states to monitor the services and payments associated with the Medicaid Program. The Food and Drug Administration is experimenting with MMIS as a source of information on drug-induced illness.[14]

The issues involved in detecting drug-related illness have been thoughtfully examined by Jick, *et al,* on the basis of their extensive experience in the Boston Collaborative Drug Surveillance Program.[15] They recommend computerizing the pharmacies of fixed population groups that are able to identify hospitalizations within their membership so that hospital diagnoses may be linked to previous drug use.

When specific effects have been identified or suspected, case-control studies can be very effective in quantitating relative risks, provided that the underlying records of exposure are accessible. Large-scale information systems of potential value in such research include those of the Commission on Professional and Hospital Activities-Professional Activity Study, affiliated with the American Hospital Association[16] and the Veterans Administration.

To cope with the increasing demands of our society for prevention, treatment, and compensation, we need more, precise, information on health hazard; yet we have not been willing to face up to the implications of these needs. To satisfy them will require better planning and integration of existing information systems, additional funds, and some trifling sacrifice of personal privacy. Technical improvements in record content and provision for record linkage under controlled conditions would serve the needs of medical science adequately without requiring the creation of the huge data banks that many fear unnecessarily.

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