

**VITAL and HEALTH STATISTICS**  
DOCUMENTS AND COMMITTEE REPORTS

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# Report of the Twentieth Anniversary Conference

Of the United States National Committee  
on Vital and Health Statistics

Discussion of three problems in the gathering and use of health statistics: quaranteeing the basic rights of individual data sources; determining current needs for these data; and indicating ways in which National Committees can contribute to their development.

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U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE  
Public Health Service  
Health Services and Mental Health Administration

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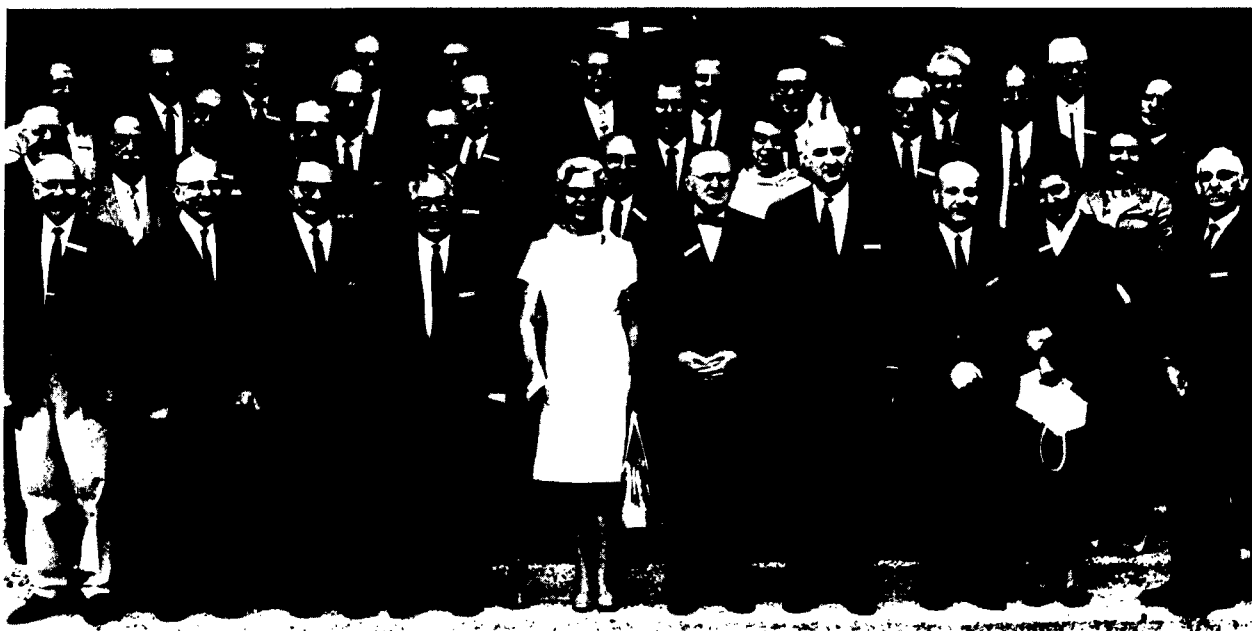
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# FOREWORD

The U.S. National Committee on Vital and Health Statistics was established in 1948 at the recommendation of the First World Health Assembly to advise on matters relating to vital and health statistics and to promote and secure technical developments in the field of vital and health statistics. More recently the U.S. National Committee on Vital and Health Statistics was designated as a public advisory committee to the Secretary, U.S. Department of Health, Education and Welfare.

To commemorate its 20th anniversary, all the past and present members of the Committee, and representatives of National Committees of several countries were invited to participate in discussion of some of the issues of the day in conducting surveys and collecting and using health statistics.

## CONFERENCE PARTICIPANTS



From Left to Right:

Front Row: Dr. Clyde V. Kiser, Dr. Conrad Taeuber, Dr. Philip M. Hauser, Dr. I. M. Moriyama, Mrs. Margaret F. Shackelford, Dr. Edwin L. Crosby, Dr. Robert L. Berg, Dr. Edward R. Schlesinger, Dr. B. Skrinjar, Dr. C. Horace Hamilton

Second Row: Dr. John Storck, Dr. George Baehr, Dr. E. F. Krohn, Dr. Franklin D. Yoder, Dr. Donovan J. Thompson, Mr. Fraser Harris, Dr. Meindert J. W. de Groot, Dr. Everett S. Lee, Mr. Walt R. Simmons, Dr. Ruth R. Puffer, Dr. William R. Gaffey, Dr. Robert Dyar, Mr. Theodore D. Woolsey, Professor Bojan Pirc

Back Row: Dr. Forrest E. Linder, Mr. Donald J. Davids, Mr. Walter J. McNerney, Dr. Paul M. Densen, Dr. Herbert E. Klarman, Dr. O. K. Sagen, Dr. Elbridge Sibley, Mr. Michael Reed, Dr. Odin W. Anderson, Dr. Halbert L. Dunn

Conferees not shown: Mr. Loren E. Chancellor, Dr. Brian MacMahon, Mr. Robert Parke, Dr. Eugene A. Confrey, Dr. Joseph T. English, Dr. Alice M. Rivlin, Mr. Lawrence Speiser

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*THIS REPORT summarizes discussions that took place at the 20th Anniversary Conference of the U.S. National Committee on Vital and Health Statistics. Present and past members of the Committee met with invited guests, including foreign colleagues, to consider three problems of general concern to workers in the areas of demographic and health statistics:*

*(1) What steps should be taken to protect the basic human rights of the individuals from whom the data that yield these statistics are obtained? Emphasized, on the one hand, were the privacy rights of these data sources during the gathering, processing, and use of the statistics; and, on the other, maintenance of the confidentiality of the information secured. The individual's right to privacy and society's needs for information must be reconciled.*

*(2) What are currently developed needs in: (a) health statistics; (b) health services resources and utilization data (c) demographic statistics; and (d) demographic and health statistics to formulate public policy?*

*(3) How can work in the areas of demographic and health statistics, national and international, be advanced by National Committees?*

*Eight invited papers are presented in abbreviated form along with summaries of the comments by assigned discussants and the main points made in extensive general discussions.*

# TWENTIETH ANNIVERSARY CONFERENCE

## OF THE UNITED STATES NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

Reported by

John Storck, Ph.D., Consultant, *National Center for Health Statistics*

Past and present members of the U.S. National Committee on Vital and Health Statistics, a public advisory committee to The Secretary, Department of Health, Education, and Welfare, met in Washington, D.C., on June 3-5, 1969, together with some of their foreign colleagues to commemorate the 20th Anniversary of the Committee's creation. The present document is structured according to the Conference agenda.

The following presentation emphasizes substantive points receiving considerable emphasis, and therefore omits many of the contributions of individual conferees. Since the document merely summarizes a discussion, it should not be concluded that either a consensus is implied, or even a full presentation of individual opinions. Some rearrangements, condensations, and minor editings were made. It is regrettable that this summary does not do justice to the spirit—even gaiety and verve—that enlivened the meeting and enhanced its solid foundation on the varied experience and sturdy intellectual grasp of those who shared its deliberations.



# INTRODUCTION

The Conference was opened by its Chairman, Dr. Berg, who outlined its scope and described its Conference-related publication plans, which include the present summary and certain documents on the privacy-confidentiality problem that may be of use in the collection and use of statistics. He also introduced the foreign experts attending the meeting. Dr. Skrinjar conveyed the greetings of the World Health Organization (WHO) to the National Committee. She called attention to the fact that WHO is studying ways of fostering international collaboration by improving its information exchange service, and solicited the support and cooperation of the National Committee in this effort.

## WELCOME BY DR. ENGLISH

In his welcome to the Conference, Dr. English stressed the current situation in providing health services to satisfy the country's needs, and emphasized the functions that the National Center for Health Statistics (NCHS) must perform if current and rapidly developing needs are to be satisfactorily met.

The Department of Health, Education, and Welfare is presently developing plans extending through fiscal year 1975. Fundamental facts are urgently required to give this planning a solid foundation. To an unusual degree, these facts must be of wide scope, detail, depth, and complexity if the planning is to meet the country's current and expanding needs. While purely health considerations are highly important,

*every issue has to relate to the larger issue of what is going on inside the country.... It is impossible to have domestic tranquility in the land if the health care needs of the American people are not met.*

Our problems in providing for these needs involve everyone, although they are more dramatically obvious among the poor. The planning problem has become more apparent and urgent because Americans are becoming more aware of these needs and of the possibility of satisfying them. Among other consequences, this has been a

factor in producing "a galloping inflation in the cost of health care," at double the rate of price increases in the rest of the economy.

While the Federal Government obviously must participate in protecting and improving the country's health, the Federal strategy of investment in health is undergoing extremely close examination at the present time. The Nation's health is too valuable to the country and to its individual citizens, both immediately and as a future source of increased productive capacity, purchasing power, and life satisfactions, to give point to the thought that access to them should be limited or rationed; nor would any sector of the population be satisfied if health efforts directed toward them were curtailed. We must develop better ways of delivering health by increasing the capacity of both private and public health care resources.

As an example, Dr. English pointed out that 30 percent of Medicaid funds are supporting nursing homes for the aged. The average length of stay in these homes is about 4 years, and typically terminates in death. While this use satisfies an important need and can easily be justified, there is also, for example, a real need to deliver high-quality health care to mothers and children and young families, where the social and personal return in years of more healthy living would be very much greater.

As the continuing and complicated integrated planning goes on, we must make certain that the planning structure itself does not needlessly proliferate after the earlier manner of the health services structure. "When you have good data you have the first leverage for rational and solid action." For such data the Department is depending largely on the National Center. But there is a need for more than national data, or data concerning large sectors of the country. As workers again and again point out, they need data concerning their own communities. We can help here by conducting area surveys to measure local needs, as recently has been demonstrated with respect to hunger and malnutrition needs. Because of the success of these surveys State Governors are now asking us for technical assistance so that they can conduct their own surveys. Here too the Center can help.

Needed also at the Federal level is a national surveillance system to determine the nutritional status of our people. Here too the Center will help. The sampling must be of high quality, since many may be inclined to question the findings. Dr. English observed that the nutritional surveillance system will probably be only one of a number of major problems on which the Department will be seeking help from the Center. Some of these needs will call for expansions of statistical expertise.

Although we have a variety of ways for delivering health services to the American people, we need many others. We also need more cooperation between agencies.

*We have learned that if you set up responsive and accessible comprehensive health care services, people will use them, including people who may not now be getting any care at all.*

Dr. English noted a growing percentage of the country's younger physicians wish to establish themselves in ghettos and rural areas. More physicians are participating in group practice, and more who are working in poorly served areas are

organizing themselves into associations to handle the health problems of their areas.

## MR. WOOLSEY GREETES THE CONFERENCE

Mr. Woolsey noted that recent developments in public health have increased opportunities for helpful associations between the Center and other agencies, including especially some of the newer organizations in the Public Health Service whose missions have not yet been clearly defined. The excellent use which the National Committee made of earlier opportunities has had tremendous influence in the whole field of health statistics in the United States. Mr. Woolsey cited four examples: the studies which led to the creation of a continuing National Health Survey; the long interest of the Committee in a classification of diseases which could be used to develop multiple causes of death statistics; the Committee's report on medical economics; and its numerous reports on fertility measurement, culminating in the recommendation of a continuing fertility survey. The Center has not yet been able to get funds to implement this last recommendation, although it is strongly supported within the Department.

# PRIVACY AND CONFIDENTIALITY IN COLLECTING AND USING HEALTH STATISTICS

Three principal speakers—Dr. MacMahon, Mr. Speiser, and Dr. Taeuber—developed phases of this topic. Here as in other substantive discussions, each speaker was followed by an assigned discussant, before the topic was opened up for general consideration.

## Situations Involving Risk of Invasion of Privacy and Breach of Confidentiality

### PRESENTATION BY DR. MACMAHON

Dr. MacMahon confined his discussion to situations in the health sphere where

*documents are created by or about an individual and deposited outside his immediate control. There may be a legal requirement for the existence of the document, or the individual may voluntarily create it for some purpose that he himself has in mind.*

The problems to be discussed arise when such documents are used in other ways, or by other persons, than were originally contemplated.

While even the preparation of statistical tabulations from legally required documents may be regarded as invasion of privacy—since it necessarily involves perusal of the documents by persons other than those for whom they were intended—Dr. MacMahon held that there are advantages in not demanding the narrowest interpretation of our rights to privacy:

*In spite of the potential problems, few people would argue against the need for State and Federal agencies to prepare statistical tabulations from vital records and Census schedules.*

Dr. MacMahon cited many instances of the guidance made available to planners and researchers by routine statistical tabulations, as likewise by closer study of more detailed relationships: for example the impetus for our regional medical programs directed against heart disease, cancer, and stroke; campaigns to reduce the special health problems of minority groups or of particular localities, as tuberculosis among Negroes, cervix cancer among Puerto Ricans, water-borne infectious disease among American Indians; wide variations in infant mortality rates between ethnic groups and regions of the country, and even the general leveling off in the United States of a decline in infant mortality rates that had extended over many decades; and most dramatically, light on

*this century's remarkable epidemic of lung cancer—an epidemic which has caused more than a million deaths in this country alone in the last 50 years. The hypothesis that cigarette smoking is the cause of this epidemic was sparked by the close correlation between the increasing consumption of cigarettes and the rising death rate from lung cancer.... It is questionable whether this trend would have been observed unless routine tabulations had been made from death certificates—certainly its extent could not have been documented.*

However, much more concern about invasion of privacy is felt when the use of records requires identification of the specific individual. There are two general situations: when the record is used to identify a group of individuals with certain characteristics concerning whom additional data are sought (followback studies), and when the information on one record is linked to that on another record pertaining to the same individual who does not know that the records are being associated (record-linkage studies). In either instance, the records involved need not be vital records; for example they may be hospital records, or records obtained from disease or other registers, or the records may come from nonhealth-oriented sources.

John Snow used the followback technique around 1850 to demonstrate that cholera was being transmitted through London's water supply in certain areas. His studies enabled effective pre-

ventive measures 40 years before identification of the microorganism responsible for the disease. Hundreds of followback studies involving many health conditions related to many areas, have been used to investigate public health problems. As a recent example sponsored by the National Center,

*postal questionnaires to samples of women identified from birth certificates and infant death certificates are providing previously unavailable national data on the relationship of fertility and infant mortality to social and economic factors and to the mother's previous reproductive history.*

Use of records for followback to the patient or other informants has been undertaken for medical-care purposes or for the protection of the community's health, as well as in research. An important instance, clearly requiring a breach of the patient's confidence on the part of his physician, is the legal requirement for notification to governmental authorities of certain contagious and infectious diseases, including venereal diseases.

Records themselves can be linked without followback whenever they can be referred to an identical origin, as to a person, family, business firm, location, or other specific means of associating separated pieces of information. Such linkages are now commonplace in the business world and also to the Internal Revenue Service, in the effort to cope with a rapidly increasing volume of information about an ever-growing population. The computer greatly enlarges our capacity to make record linkages. However, there are specific reasons in the health area for an increased interest in record linkages:

*These include the country's greatly expanded effort in medical research in general, the increasing recognition of the community's responsibility for the health care of its individual members, and the shift in concern from the acute infections to the chronic diseases which have insidious onsets and often intervals of several decades between the occurrence of causative events and the appearance of clinical disease.*

Over such long periods memory of possibly causal events is a poor substitute when records might be available.

The potentialities of record linkage in the health field have hardly been tapped. With a routine system linking the major sources of medical data, one might learn much about the long-term outcome for infants exposed to special circumstances during pregnancy and delivery, and treated in different ways; the long-term effects of a child's environment on his physical and mental health as an adult; the later mortality and hospitalization experience of groups of persons inadvertently exposed to suspected noxious agents; the illness experience of persons whose occupations expose them to suspected toxic substances; the long-term mortality of persons receiving different forms of surgical or medical therapy; and the risk of occurrence of specific diseases in the parents, children, and siblings of affected individuals. Centralized record linkage also would greatly facilitate diagnosis and therapy in providing medical care. Through the operations of the Follow-up Agency of the National Academy of Sciences, based chiefly on the records of the military services and the Veterans Administration, where filing of claims for veteran death benefits allows identification of over 95 percent of all veteran deaths, the long-term effects of specific military experiences and the possible relationship of these experiences to such consequences as subsequent risk of cancer have been studied. The addition of birth certificates in the study of the deaths of military veterans has enabled establishment of a roster of twins, on which a considerable number of special studies already have been based.

The present decentralization of records in the United States imposes serious limitations on the use of record linkage. Here arises one reason for various proposals aiming at a more unified national statistical system. One step forward would be establishment of a national death index permitting identification of at least the time and place of death of indexed individuals. This would help at least to locate where the records of those included are filed, and at a minimum would help to clear files of these names. A more fundamental solution, at least for the employed population, would be to make the data on Social Security records available for medical research. To do so, however, would

*raise important issues of privacy—including philosophical questions as well as the practical problems that would arise from restrictions of access to files and limitation of access to authorized personnel. In my own opinion—and this is no more than a guess—the opening up of the Social Security System for medical research purposes would be perhaps the most significant advance in the utilization of routine records that might be contemplated at the present time. It is also one of the most sensitive areas.*

In Dr. MacMahon's judgment, the opening up of the Social Security files for medical research—of course under stringent safeguards—"would lead to an advance comparable to those brought about by the work of Graunt or Farr, and by the creation of the National Health Survey in 1957."

#### Discussion

Dr. Dyar, the assigned discussant of Dr. MacMahon's presentation, sought to identify the basic reason why so many are alarmed at the proposed enlargement of available information relating to themselves and their affairs. "It seems to me that the basic reason for concern is to be summed up in one word, and that is the word *uncertainty*." In the spectrum of possible queries, where does the need for privacy begin? Obviously the answer will vary according to circumstances. What is a sound working definition of confidentiality? Further, how much information does society need? Where should the right of the individual take precedence over the needs of society?

We are uncertain also as to the bases on which our actions rest:

*One of our weaknesses as health people is that we have limited our discussion to ourselves, and have not involved others who might make a major contribution here: the lawyer, the philosopher, the sociologist, and particularly the consumer himself.*

The problem is aggravated because we are living in a society that is undergoing changes in its values. There are discrepancies between standards of individual and public conduct. We

are apprehensive concerning our legal rights. We may even be worried by the ingenious reasonings of epidemiologists. "There is a whole new group of technologies and methodologies that heightens apprehension." People worry about computers, case registers, data banks, and inferences drawn from combinations of records.

*We are going to have to devote some of our efforts to the resolution of the uncertainties that surround situations involving the risk of privacy invasions. This is especially necessary when they relate to uncertainty of policy on the management of data, and secondly with respect to the ways in which the consumer or the public may be involved in the making of policy and in decision determination.*

In the ensuing general discussion Dr. Hauser described the fear about invasions of privacy as "a cultural atavism not relevant to our present-day metropolitan mass society." It is associated with a fear of government, which needs more information as a basis for policy and action and evaluation of ongoing programs. Actually, the private sector much more than government is actively and even viciously infringing on our privacy, as in the passing around of credit information and misinformation without any controls whatsoever. It is true in government also, however, that attention needs to be given to control agencies accumulating dossiers about individuals with inadequate critique of the statements that are allowed to enter the files.

Dr. Hauser noted that statistical files are subjected to controls, checks, conformance requirements for accepting data, etcetera. In contrast with a defensive position, therefore, "what is needed is a very positive and aggressive program to provide the general public with an education on the actual situation."

Dr. Gaffey felt that we should meet "the problem as it is perceived by most people," which is based partly on such reactions as a vague general opposition to things like computerization. The present clumsiness of our record-keeping system is a sort of *de facto* protection of privacy. However, as the system is improved, "we must protect privacy by some sort of legal explicit safeguard, or code of ethics, or what have you."

At this point a number of speakers suggested the possibility of "trade-offs" as between private demands and public needs. Central to this would be the need for a "broader understanding of what we are up to":

*Our profession has failed to explain to the public that there is such a thing as collecting information for general use: not for the sake of doing something to the individual or about the individual, but rather for the sake of assembling a mass of information which is going to be used without any direct reference to the individuals who provided the information.*

It was emphasized, however, that this did not quite cover everything. The public wants both not to be tattled about and not to be annoyed:

*I think a lot of the public objection now to interviews and questionnaires is not that they are afraid somebody else is going to find out the answer. They are just annoyed at being asked too many questions too many times by too many people. It is an invasion of privacy even if they are completely assured that nobody will ever see their answer besides the interviewer.*

The Office of Management and Budget, Office of Statistical Policy was established in part to prevent undue annoyance of respondents.

Other questions arise with respect to the accuracy and fairness of the information lodged even in statistical files. It was suggested that any person should have the right to learn what information is located against his name "and to respond to the record keeper with such corrections as may be necessary." This becomes especially important when a record is used not only to produce statistical information, but as legal or other evidence of particular facts. Not discussed were the problems that might arise if records were freely open to inspection, or the obstacles to their evidentiary value that might be created if they were liberally amendable.

It was pointed out that privacy invasion is a subjective variable:

*What is an invasion of privacy to one person may be completely inconsequential to another person. Also this changes with the times. The social scientists and legal scholars should come up with something better than these private judgments.*

Perhaps the point of control should be located in penalties for the misuse of information. Dr. de Groot held that "the question of privacy should not be within the discretion of the public. They will tell everything, not only to medical men, but to everybody."

There was considerable discussion as to who can now obtain certain specific kinds of health records, and as to who should be able to get these records. The principle that medical records should be made available to patients only with the consent of his physician sounds reasonable; but many questions and problems would remain. Would the permission be necessary to deposit the data in a computer? Is the physician equipped to decide who shall use the data? Can a permanent decision safely be made in what may be a changing situation? What would happen to medical research if records are open or closed according to obscure criteria? In particular, would follow-back studies languish? Dr. Crosby discussed the general question in terms of hospital medical records:

*To all intents and purposes, the hospital medical records are not confidential any more. In addition to the privacy of the individual, the privacy of the physician is at stake in many instances because of the malpractice suits now spreading throughout the country. Then too, about 75 percent of all patients admitted to general hospitals in this country are covered by some form of insurance, and the commercial insurance companies are insisting that the records become available to them without the patient's consent.*

While it is true that malpractice suits open up the patient's record to the court only if the patient has entered an action himself and theoretically only to the extent that the record is relevant to the damages claimed, there are ways of getting around this, as through issuance of sub-

poena by the court, or by opening the medical record to the insurance company through a condition in the initiating contract.

Mr. Woolsey proposed that one ask what are the ways privacy might be invaded by surveys, assuming confidentiality has been assured. There would appear to be five ways in which the citizen's privacy may be interfered with:

He is not left alone. Is this a dead issue in today's society?

He is interrupted in his activities.

He may be irritated, as by the number or nature of the questions.

He can be frightened. "When people do not understand what you are doing they may be frightened."

Sometimes he is put to some expense, especially when data are collected from establishments.

In addition to seeking ways to protect the confidentiality of records used for statistics and research, this Conference might well address itself to privacy questions like the above, leaving it to others to work out their legal expressions and ramifications.

Dr. Puffer suggested that the legal aspect of such events as birth and death be separated from the additional information now included on the legal certificates but required only for statistical and research purposes. For legal purposes there is a need for what might be called the fact of death and the fact of birth, including of course certain additional information such as names, date, place of occurrence, et cetera. The legal record would be open to the public. For analysis, as into congenital malformations, multiple causes of death, and so on, much more is needed than is required for the legal record, involving medical records, hospital records, autopsy records, and much else.

Dr. MacMahon thought that permission to use hospital records for analysis might well be obtained when the records first originate. "I think that in fact both the people involved and the physicians are amazingly free with the information when their cooperation is requested."

# Protection of the Rights of Participants in Population Studies and Surveys

PRESENTATION BY MR. SPEISER

Mr. Speiser accounted for the current concern with the privacy problem by the increasing adoption, since 1945, of surveillance technologies that had long been available, although largely in less developed forms. These spread in use among law enforcement officials, government regulatory agencies, businessmen, civic groups, behavioral scientists, and others. Simultaneously the arrival of the computer entirely altered quantitative possibilities with respect to information collecting and storing, at a time when American law and public opinion were slow in adapting themselves to the changing situation. As Westin has suggested, this lag may have occurred because of delays in the replacement of previously accepted assumptions about decision making. It had been assumed that decisions were best arrived at by individuals using a combination of direct judgments of situations and abstract reasoning. This basis for planning began to be replaced by a "predictive theory of information" centering around the massing of data interpreted through the techniques of statistical methodology.

The right to privacy, which Judge Thomas M. Cooley in 1878 was first to call "a right to be let alone"—a phrase quoted by Warren and Brandeis in a famous 1890 Harvard Law Review article and by Brandeis in *Olmstead v. United States* (1928)—even now is "being worked out on a case-by-case basis." Hence as regards the rights of participants in population studies and surveys, "we do not yet know what they are." We do know, however, that Americans are very sensitive as to questions asked in certain areas, especially by government agencies. One of these areas is religion, although from 1850 through 1936 the Bureau of the Census did make a half dozen counts of religious affiliation. Sex questions have been another sensitive area, as likewise details as to reading habits:

*It is clear that any compulsory questioning of Americans by the government about what they have read and what books they have in their homes, would be unconstitutional. What is not clear is whether a voluntary government survey would be unconstitutional, although my judgment would be against its validity.*

In a free society, we are entitled to have "hidden thoughts, hidden practices, hidden interests," to live safely behind our "psychological armor," to be assured of "the emotional relief of letting one's hair down in private." Such preferences and requirements reach far beyond assurances of confidentiality.

*When we talk about the right of privacy, we mean the right of an individual to keep information about himself or access to his personality completely inaccessible or secret from others.*

*Confidentiality, on the other hand, is concerned with the disclosure of certain information to another person for particular purposes. It is dependent on either an express or implied agreement between the two to restrict the information to themselves.*

The widely recognized doctrine of consent requires that permission to divulge information be freely given and that it be informed. Voluntary consent agreements

*do not really help much if there is a disclosure beyond that agreed to, or if there is an invasion of privacy which is not warranted by the type of survey conducted.*

Indications to respondents that a survey is voluntary are often less than candid, leaving shadowy suggestions of compulsion.

While the Public Information Act of 1966 makes Federal Government records and information more accessible to the public, it specifically exempts "personnel and medical files and similar files, the disclosures of which would constitute a clearly unwarranted invasion of personal privacy."

Mr. Speiser next considered various proposed techniques for protecting the public against information intruders. Imposing criminal penalties for breaches do not hold much promise, especially where the breaches have been made not for personal gain but in the interest of science or social good. "Over-zealousness by statisticians" probably would even less frequently be punished than over-zealousness in upholding the law on the part of enforcement agencies.

Civil remedies against disclosures through court actions for damages usually must prove actual financial loss or physical or mental suffering as a result of the disclosure; and such legal actions are slow and expensive. Injunctions against future disclosures are of questionable value after the disclosure has occurred. In addition, a suit circulates the information, false or true.

Administrative controls may be developed to prevent breaches of confidentiality:

*Here in the District of Columbia, the United Planning Organization has created a trusteeship in which the three trustees are legally responsible for maintaining confidentiality and anonymity of those on whom information is collected. It remains to be seen how this will operate in practice and how effective it will be.*

As a final possibility, an advisory committee composed of statisticians, lawyers, representatives of public groups, and others might be created to determine how information is collected, what measures are being taken to maintain confidentiality, and what should be done to deal with individual complaints against breaches of the system. Here as elsewhere, "it is the human equation and not the methodology that can provide the final measure of protection."

In conclusion, Mr. Speiser spoke of

*the seeming insensitivity of many social scientists because of their feeling that because they are men of good will acting for the public good, neither their motives nor their methods may be questioned. The furor over the proposed National Data Center is an example of the public concern which arose because of the apparent lack of concern of government efficiency experts toward the right of privacy.*

Mr. Speiser characterized this as "a combination of bad politics and poor thinking."

## Discussion

The assigned discussant, Dr. Confrey, cited Alexis de Tocqueville and John Stuart Mill to show that the need to balance fundamental rights is no new problem in democratic societies. As liberals, both staunchly believed in egalitarianism and majority rule, but they also saw that too great emphasis in this direction could threaten individual development. They went on to a concept of balance as one of the continuing needs in a democratic society.

Dr. Confrey circulated a document (dated May 1, 1969) prepared by the Division of Research Grants, National Institutes of Health, entitled "Protection of the Individual as a Research Subject" which in seeking to maintain this balance in research conducted by the Public Health Service,

*relies very heavily on a local committee at an academic institution to study the protocol of its research project proposals to make certain that the rights and welfare of the individuals involved are adequately protected; that there is sufficient and proper attention to informed consent, and that the risks in the research are outweighed by its benefits or the importance of the knowledge to be gained.*

The booklet states that acceptable assurance of compliance must cover the following:

*"Statement of principles concerning the treatment of human subjects."*

*Description of membership of the review committee, which "must be composed of sufficient members with varying backgrounds to assure complete and adequate review of the research," and not include any persons who are involved in the research activity.*

*"Description of the initial and continuing review procedures to be followed by the committee."*

The position taken by the National Institutes of Health on the conduct of research attempts to



maintain balance. This has not been the case with all of those who have been warning the public that their privacy is being endangered by almost any research whatsoever. Balance is not being maintained when the proposal for a national data system is characterized as aiming to set up a great expensive garbage pail. (Dr. Berg interposed to say that McLuhan had called it "one big gossip column.")

Mr. Speiser was asked during the ensuing general discussion whether confidentiality could in fact always be maintained in court actions—whether, for example, data on narcotism obtained by a sociologist could be subpoenaed when one of his respondents was accused of a criminal act. He replied that this would depend on the law of the particular State. The common law recognizes only two confidential relationships—between husband and wife, and between attorney and client. Most States now include doctor and patient, while some add religious leaders and their communicants, or newspaper reporters and their informants. Information collected for statistical purposes certainly can be subpoenaed:

*A judge may be willing to quash a subpoena because he has the right to do so and concludes that various social interests would be better served in that way, but confidentiality is not otherwise protected from subpoena in the absence of a specific statute.*

Mr. Speiser did not feel able to decide whether a researcher might be subject to a damage suit if he divulged confidential information under subpoena. He felt, however, that the case would not be likely to arise; the researcher might be pushed by a subpoena threat, but not to the final point of its being issued. So too with priests; they are not likely to be required to disclose what they hear during confessions, even in States where they have not been granted the confidentiality privilege.

Mr. Woolsey wondered whether the legal compulsion to answer census questions had not been a good thing so far as the public is concerned. "The questions certainly get far more public scrutiny, and Census has been more careful in the questions that are asked." But what of the thousands of purely statistical investigations where there is no compulsion to reply?

*What does informed consent mean in these situations? Is it enough simply not to say that the information is required by law? Some say you must definitely tell the respondent that his response is not required. If we do not say this in so many words, I think most statisticians would agree that they get a large enough degree of response to make the results valid; but what would happen to the data if we made a specific statement of nonrequirement? Would the information become essentially unusable?*

Mr. Speiser replied that the law on consent is currently being spelled out by the Supreme Court in the criminal law field. After years of battling, in the famous *Miranda* case the Court held

*that the police had to state, you have the right to remain silent; anything you say can be used against you; you have the right to have an attorney; if you cannot afford an attorney, one will be provided for you; and you can stop answering questions any time you want to.*

Mr. Speiser felt that only research could determine the consequences that would flow from complete candor in the case of statistical studies.

Dr. Hauser stated that, although he recognized that the American Civil Liberties Union is an essential part of our society—"we need this kind of watch dog"—like any person or organization it can go too far. "I too think the key word is balance." We are not acting in a balanced way if we try to handle 20th century problems with 18th or 19th century ideas. "This is to ignore the context in which the problem arises." By applying 18th century guarantees and limitations, perfectly reasonable in their time, to organized crime in the 20th century, the United States has made itself incapable of protecting itself against its deprecations. A mass society needs to recognize basic rights possessed by the collectivity—including security—which are of equal importance with the individual rights emphasized by our Constitution:

*We must weigh the welfare of the public against the privacy of the individual. He can be fully protected so far as statistics are concerned by the confidentiality requirement.*

Mr. Speiser replied, "I don't think you are running with the tide there."

*I think you are bound to be a loser on that. The Bureau of the Census could very easily head off a great deal of criticism and save some of the time spent in defending itself by providing better justification for asking questions rather than basing its argument solely on confidentiality.*

Dr. Klarman doubted that the concept of balance in the end would prove very helpful:

*Implicit in the notion of balance is the assumption that ultimately there is a harmony of interest among the objectives of the parties. But there is the possibility that they may be in real conflict. In that event balance offers no satisfactory solution. Much better is the notion of trade-offs. To what questions must we have the answers? What questions can we give up? To what questions can answers be obtained by other mechanisms? For example, perhaps we should require everyone to file an income tax return, and stop trying to include income reporting in the census.*

Dr. Dunn proposed a double set of files: one consisting of the statistical data, the other relating these data to their sources—individuals, firms, or whatever. This second file would be put under ironclad controls. Dr. Berg noted that the District of Columbia United Planning Organization has established just this dual system. There is one file containing only the names of respondents, with their identity numbers, while the second file, arranged by these numbers (and without the names), contains the statistical information. Mr. Speiser had briefly described this system, but now observed that "ironclad controls" are impossible—"you cannot guarantee that the system will never be broken." Nor can you guarantee that the system can be used only for statistical purposes, as opposed to surveillance uses. You cannot guarantee that the key code will not be subject to subpoena. Nor can safety be guaranteed against blackmail.

Dr. Hauser suggested a solution through use of a triple system. Let the ability to open the system at all be located at some place in the Executive Office of the President, possibly in the Office of Statistical Policy. Here only would

the key be located. "The President can resist subpoena, and he can resist Congressional pressure under the check and balance system." Information would be located in machine readable form in the statistical system, separate both from the list of information sources and from the key which enables these two to be united with each other.

*This kind of system has been working for years in other contexts. Here it would be further protected by the separation of powers, and by the fact that the statistics are stored only in machine-readable form.*

In further discussion, Dr. Hauser suggested that data might be submitted in sealed envelopes, with personal identification appearing only on the envelope itself. The system identification number for that person is put on the envelope, which is destined for secret storage. The enclosed data, with the system identification number added to it, enters the statistical file. Such a process would make personal identification extremely difficult.

With respect to the Current Population Survey, maintained by Census without the compulsory provision, response is much higher than for private collection agencies. Of course most of the public assumes they must answer these questions, since they come from the Bureau of the Census. Recently, because of the publicity, nonresponse has increased somewhat for the Current Population Survey, and considerably for some private surveyors.

It was noted that all the Census questions should be on a comparable basis, so that they can be related statistically to each other. Methods should not be mixed needlessly. It also was pointed out that Census has had to invoke its compulsory powers only very infrequently. Mr. Reed stated that about 80 persons had been prosecuted for non-response on each of the last two United Kingdom censuses, with convictions secured in all cases. The penalty ran from about two to a maximum of 10 pounds. Incidentally, birth and death records in Britain in no way are confidential documents:

*Anybody who knows the name and date of birth of anybody born in England or Wales can discover whether or not he was illegitimate, whether he was adopted. He cannot discover who his natural parents were; that is confidential by statute.*

General browsing in the records usually is not allowed, although even permission to do this sometimes is obtained by researchers.

Mr. Reed suggested that "Surely there is a real difference between asking a person what his religion is and interfering with his religion. And so too with race." Some conferees doubted this. He also thought that the data-collection agency might be made responsible, not to the executive, but to the legislature. "The press also could make a good trustee." Other suggestions of an overseeing group mentioned in the discussion were a general control commission and professional association.

In France, Dr. Guidevaux noted, only routine information on the population is compulsory, including recently a few cultural and educational questions. On deaths, only the legal registration of death is compulsory; the physician may entirely omit the cause of death. At the central agency in Paris there is no way of linking a cause of death to an individual patient; if reported, it is on a separate document.

In Yugoslavia, Dr. Pirc testified, all routine birth and death data can be obtained from the local registrars. Whatever questions are asked in a given year must be answered.

In Scandinavia, Dr. Krohn stated, the whole question is not considered important; open access to records has never led to any trouble. Only detailed medical information is confidential. Yet copies of certificates including the cause of death are fairly freely available. Scandinavian countries have a unique registration number for each individual which goes on every record pertaining to him.

Dr. Berg stated that the Gallup organization has found quite uniform refusal rates of about 5 to 7 percent irrespective of country, in spite of the many differences in the availability of governmentally gathered data.

It was suggested that statisticians should find out in what degree lack of compulsion in answering affects the data.

## Issues in Confidentiality of Information and Ways of Avoiding Breaches of Confidentiality

### PRESENTATION BY DR. TAEUBER

Dr. Taeuber focused discussion on information collected by the Federal Government for statistical purposes. Whether the information is obtained on a voluntary or mandatory basis, the collectors invariably seek to prevent misuse of the data, by themselves as well as by others. Only persons specifically entitled to handle the source documents are permitted to do so, and disclosure analysis guarantees that published compilations do not directly or indirectly reveal individual information.

Replies to our decennial census are mandatory, while the Current Population Survey is largely conducted without the power to compel a reply. In both cases the same confidentiality and privacy provisions apply. Thus with respect to the latter,

*Every proposed new inquiry is subjected to careful consideration from the point of view of essentiality, as well as the possibility that the query would be considered as an improper invasion of individual privacy by a significant number of people. Collecting information on possible public reaction is an important part of any pretest.*

*The provisions against disclosure of individual information make no distinction between good and bad uses, nor do they give the Director of the Bureau the option of deciding that a piece of information might be used to the advantage of the individual and, therefore, may be released to a third party without the prior written authorization of the individual concerned.*

The Bureau of the Census has established special safety criteria that allow it to maintain confidentiality while making special tabulations based on Current Population Survey returns. When computer tapes or punchcards are made available at locations away from the Bureau's headquarters, they remain in the custody of Census employees, even though names and addresses are not included, so that inadvertent disclosures do not ensue.

After other records have been matched with Census information these records cannot be returned to their sources, since unusual items on them might provide a basis for recognizing individuals to whom specific census information applied. Under the Census law, even the address of an individual which was received in connection with the Bureau of the Census activity must be treated as confidential.

Identifying information in censuses dating from 1900 and thereafter is never released to the public. This sometimes irks genealogists.

As the time for taking a census approaches, special care is taken to let the public know that Census schedules are kept fully confidential. Thus a Presidential Proclamation in 1960 assured the public that "There need be no fear that disclosure will be made regarding any individual person or his affairs." In greater detail:

*Individual information collected in the Eighteenth Decennial Census will not be used for purposes of taxation, investigation or regulations, or in connection with military or jury service, the enforcement of school attendance, the regulation of immigration, or the enforcement of any individual State or local law or ordinance.*

Census has supported its confidentiality provisions by resisting subpoena in court actions. In 1962 Congress amended Title 13 of the United States Code when a Supreme Court decision concluded that a business firm's file copies of its replies to a Census questionnaire were not subject to the same confidentiality treatment as the original filed with Census. As a result they now have the same confidentiality status as the original questionnaires.

In concluding his paper, Dr. Taeuber stated that "the statistical system needs both the fact

and the image of treating individual information as confidential."

## Discussion

The assigned discussant was Dr. Sagen. He found the confidentiality-privacy problem simple only on the surface. "Informed consent" for example is a nice phrase, but what does it really mean? Again, how do we balance the right to privacy against the right to know? In Missouri the *St. Louis Post-Dispatch* got State legislation making birth and death records completely open to publication, much to the chagrin of registration people. New York State has printed a release form on the back of its birth certificates. The Tobacco Institute has been challenging survey findings about cigarette smoking, and may want to inspect the basic records. Photographers try to get the names and addresses of all births in their areas, and the records can usually be obtained in local vital registration offices, even though they cannot be obtained from the State registrar.

Perhaps, Dr. Sagen concluded, we should have two vital documents for each kind of event: a legal document of record, and a statistical document including whatever information we think we need. Or

*We could develop some direct way, by taking advantage of computer technology, for reporting the health information and the confidential information from hospitals or doctors directly to the appropriate statistical agencies. This would have other merits besides preventing breaches of confidentiality.*

In the general discussion, Mr. Reed saw problems in setting up two birth certificates. As an example, the names of the parents certainly would be needed on the legal document, but this immediately identifies illegitimacy and adoption.

Dr. Sagen strongly advised that consideration be given to keeping jurisdiction over bodies of data decentralized while developing linkages between the data. Those who are collecting the information have the best knowledge of its reliability and the best understanding as to what data can be released. It would be a virtual impossibility for some super-agency to make good decisions of

these kinds over the entire data spectrum. It should not be imagined that local jurisdictions are incapable of maintaining confidentiality. In New York City for something like 25 years only an official civil servant is entitled to know what cause of death appears on any particular death certificate. Insurance companies have challenged this policy a number of times, but always without success. In discussion, it came out that the policy originated in an effort to improve the reporting of deaths from alcoholism, venereal disease, et cetera. There was little evidence of improvement, except temporarily.

Dr. Sagen doubted that the National Center should confine itself to information collected by its own mechanisms. "Should we not also take advantage of hospital records and other information collected for special purposes?" He also thought that public policy on safeguards against the invasion of individual privacy should be accommodated to the public interest, particularly research which benefits all.

In the ensuing general discussion, scepticism was voiced by Dr. Lee as to the wisdom of trusting to decentralization as a protection of confidentiality. Too many people with low confidentiality standards would be involved. Dr. Berg observed that two different kinds of problems are involved; unauthorized use of a whole set of records is comparatively easy, but finding records for particular individuals can be extremely difficult unless you know the exact jurisdiction.

Mr. Woolsey has found that unexpected difficulties arise in attempting to protect individuals while also serving the public interest. Thus after the National Center had carried out the difficult process of setting up a list of all the country's inpatient establishments to be used as a sampling frame for studies of the patients and the establishments, many—including some of the establishments—thought the Center should make the list public. They were being harassed by others who were also setting up lists. At first it was felt that the Center could not publish even the names and addresses of the establishments, since doing so would violate the confidentiality assurance that appeared on the questionnaire. This aroused so much criticism that the questionnaire was divided into two parts. The public part gave the name and address of the establishment and certain identify-

ing information such as number of beds, average patient load, et cetera. The confidential part included such items as policies regarding admission of certain types of patient, the racial composition of patients and others.

Dr. Linder questioned the wisdom of this decision:

*As soon as an agency has different sets of records, some of which are confidential and some of which are not, the principle that the agency is operating under strict confidentiality is eroded. You cannot expect the public to differentiate clearly between what will happen to particular pieces of paper. I think the Federal agencies are in their present difficulties because they created this problem by not taking a clear and categorical position on the question of confidentiality.*

*With respect to the nursing homes, it would not be enough to publish the names and addresses. To get a useful list, you need to add something about the kind of place it is. Immediately you reveal characteristics of the place that the establishments may not wish to have revealed, in relation say to income tax matters or civil rights procedures.*

*Within the Federal Government, when I was Director of the National Center for Health Statistics, we got very inadequate support from the Budget Bureau about maintaining a policy of confidentiality. I think the problems that have arisen were brought about by the lack of a clear policy position on the part of Federal agencies with regard to material collected for statistical purposes.*

Dr. Crosby stated that the American Hospital Association releases its list of some 50,000 hospital trustees only by explicit permission of its own Board of Trustees. The American Medical Association has sold its list of physicians to a commercial concern, and gets a royalty whenever that concern sells the list to one of its customers. Their list is quite accurate, and includes such information as whether this is a foreign practitioner, et cetera.

In reply to a question, it was stated that the Center probably receives more adverse reactions from its followback studies than from its surveys. The problem arises most often from death-certificate followbacks, and almost invariably because it looks as if the Center was probing into a private matter: "Why are you bringing up this painful thing?"

In response to another question, it came out that there is no place where one can discover the practices of various jurisdictions with respect to confidentiality. This might well be a study on which State registrars could help. The need is more for a summary of actual practices than for a statement of standards or goals.

Dr. Krohn observed that statistical information should not be so separated from the basic sources as to prohibit its undergoing correction when that is necessary. Dr. Guidevaux found this a regrettable feature of the French arrangement because it is not easy to query the doctor on an obviously inaccurate or incomplete diagnosis of cause of death. Perhaps the French physician would be more interested in giving the correct cause of death if he could obtain, sufficiently rapidly, useful data that helps him in his work.

Mr. Woolsey commented that the discussion confirmed the judgment that the treatment of vital records in the United States is in a pretty bad mess:

*I think it would be appropriate for the National Committee either to appoint a subcommittee itself or at least urge some other group—possibly the Public Health Conference on Records and Statistics—to take steps to investigate this question thoroughly to see if we cannot bring about some change and greater uniformity in the treatment of vital records in this country.*

Mr. Woolsey himself favored a clear separation of the legal certification of vital facts from all other information concerning these events, which should be kept confidential and used for statistical purposes only. Perhaps there should also be a public body to decide when proposed research uses warrant the revealing of names for particular research purposes.

*We are a long way from being able to implement any such proposal. The system is under the control of the States, and so far as health statistics are concerned, the Center will not release names without their permission.*

Regrettable also is the dearth of investigations into the reliability of the information as to causes of death. "It is shameful that a 1936 study by Bellows should still be our source on the reliability of deaths from venereal diseases."

Dr. Berg saw a need to record present views on the privacy of the individual and the confidentiality of information concerning him, as likewise directions of change. In the area of legitimacy, for example, there have been recent impressive changes, which have gone even further in some countries than in the United States. We can ourselves do something toward assisting in the development of a clearer and sounder doctrine of individual privacy:

*I suppose what many of us have urged during the meeting is that there be a little more inventiveness and experimentation in probing the boundaries of the privacy concept, in uncovering what the needs of the public are, and in finding out what the public will accept in developing public information in the light of the rights of the individual.*

# FUTURE NEEDS

Three sessions, chaired by Dr. Dyar, were given over to consideration of future needs in health statistics, health services resources and utilization data, and demographic statistics.

## Needs in Health Statistics

### PRESENTATION BY DR. LINDER

Dr. Linder did not try to give a full catalog of future needs for health data, as being both impossible and of little use, since neither the resources nor the ability of the statistical agencies could encompass all that is needed. Nor did he, really, have any suggestions as to what "the big thing" ought to be for the 1970's. In thinking about that, he had concluded that the health statisticians "have a hangup on a few words. Maybe we ought to try to get rid of that first."

*Small area statistics.*—This is a vacant umbrella term. The needs are different from one area to another, and "the ability of the health organization in most small areas is not up to using much in the way of small area statistics."

*Family statistics.*—"As soon as you get four or five people in a family you get too many variables. The data break down into a multitude of pieces too small for analysis."

*Longitudinal studies.*—Ignoring that they are costly and difficult, "only a narrow and very special group of studies requires the longitudinal approach." Further,

*Like family studies, longitudinal studies are hard to analyze. I do not think statisticians know how to analyze them. You get a tangled skein of individual histories that weave in and out of different classification categories, so that we end up analyzing cross-sectional cuts across an observed population. Such problems are not solved by using a computer. I am thinking of the mental limitation of comprehending a thousand different longitudinal histories weaving in and out of a dozen or more categories.*

*Record linkage and data-bank solutions.*—This is probably the most popular hangup. There is no argument that science proceeds by relating specific variables, whether for descriptive studies, analytic studies, or to draw cause-and effect inferences. If the variables you want to relate happen to be on different pieces of paper, obviously you should link the pieces of paper. But large-scale data banks are the very antithesis of this simple idea of relating specific variables:

*How much automatic, elaborate, routine machinery is it worthwhile to set up to permit you to interrelate variables collected for different purposes under disparate definitions and with widely varying degrees of reliability?*

There is no way of doing ready-made research. "Research depends on formulating a hypothesis and then collecting data aiming to prove or disprove or throw some light on that hypothesis."

Dr. Linder next considered some broad areas in health statistics where he felt more work was needed. More attention should be paid to the *fringes* of frequency distributions, as has been done with infant and old age mortality. We need to look more closely at the health of the poor, including hunger and malnutrition, but also at the other end of the scale. Perhaps the affluent are the ones who are inflating the cost of medical care. We need also to pay more attention to the fringes of the behavior distribution: to the drug addicts, alcoholics, persons with mental diseases, and more generally those on the fringes of social behavior.

*Multiple-cause analysis* is bound to receive more attention. Although the new international list should help us to conduct multiple-cause analyses, the situation remains extremely complex:

*If you start your computer going with the first cause of death, cross-classified by the second cause and by age and sex, which is the minimum amount of data needed for even a superficial analysis, you end up with a mountain of paper.*

An individual can approach this mountain with a specific problem and pull out the few cells of information that relate to what is in his mind; but what about the National Center?

*How is it going to deliver the entire mass of material to the many people around the country who want to settle a multitude of specific questions? Difficult methodological and conceptual problems are involved here.*

Another area that has been neglected is *environmental statistics*, as distinct from statistics based chiefly on political areas.

None of the topics that Dr. Linder named impressed him as indicating the big thrust for the next 10 years.

*Dr. MacMahon told us yesterday that the next quantum jump in health statistics might come from opening the social security records for epidemiological uses. That might be useful, but I do not think a quantum jump will come out of the moldy old paper that happens to be in somebody's file. The next quantum jump will not come out of an opportunistic utilization of material that was gathered for some other purpose.*

Dr. Linder then recommended that the present vital registration system be abandoned as a source of new statistics:

*I am not implying that the vital statistics system should be abandoned for legal purposes, for identification purposes, for all of its civil purposes. But maybe it is time to abandon the vital statistics system as a statistical system, and see if we cannot think of something entirely new not connected with vital registration which will give us the kind of material we need, and more material than we are now getting.*

Dr. Linder referred to earlier suggestions by Drs. Puffer and Hauser looking toward reforming the vital statistics system. He had almost con-

vinced himself that this would be possible so far as births are concerned. In connection with deaths, the data may have to be collected on something like a 100-percent basis because of the need for information about rare causes of death. Yet even here the possibility of an entirely new system deserves full study.

Dr. Linder next turned to the status of the health statistics organization within the governmental structure. When in 1946 vital statistics was transferred from the Bureau of the Census to the Public Health Service, opposition was voiced by the Director of the Census and by our colleague, Dr. Hauser. Their arguments were of two kinds. The first was that the numerators and denominators of death and birth rates should be in the same agency to guarantee uniform definitions of these elements.

The second argument was really important. Should a statistical collection activity be located in the agency that also has programming and executive responsibilities in that area? "The Public Health Service has a vested interest in whether the statistics show, or do not show, that it is doing a good job." Dr. Linder testified that over his 10 years as Director of the National Center for Health Statistics,

*The Public Health Service at no time attempted to influence the way we collected our data, or the kind of interpretation we gave to them. I cannot say quite as much for the Secretary's office. There were times when they were a little unhappy with what the statistics were saying. There were other times when there was some objection to the timing of a publication.*

But, Dr. Linder continued, the possibility of being influenced "may have more reality in a more subtle way":

*I have said many times that I did not care as Director of the National Center whether the birth rate went down or the birth rate went up; I did not care whether everyone in the country died or did not die. It was merely my job to measure the rate at which they were doing these things. But the typical role of the statistician in the health agency is to be an attorney for the cause and for the program that the health agency is responsible for.*



Since it is almost unavoidable to take this position, a truly statistical agency should not be located in any departmental unit having program responsibilities; nor should it be located in the Office of Statistical Policy or elsewhere in the Executive Office of the President, "where it would be most exposed to political pressures." It should be an independent agency, perhaps something like the Federal Reserve System, where it need not respond to a demand to produce information supporting any particular point of view.

Finally, Dr. Linder emphasized the need for training health statisticians. The universities and schools of public health are not training health statisticians in the quantity or of the type that are needed. At the University of North Carolina where Dr. Linder teaches, substantial funds have been available for training biometricians. Now money is beginning to flow into training of population experts. But there is too little money going into the training of health statisticians.

*You can talk as much as you want about data systems for comprehensive health planning at the National and State and local levels, but the people who might collect data to feed into these systems simply do not exist in adequate numbers. The schools and programs for training these people do not exist, and will not exist until 10 years after substantial sums of money begin to flow into training these kinds of people.*

#### Discussion

The assigned discussant was Dr. Densen. He said that one might differ with Dr. Linder's views in a few places, but the emphasis on the need to conceptualize problems was absolutely right. We need to focus, not on the data, not on the collection method by itself, but on adequately conceptualizing the fundamental statistical aspects of our problems. As an example of this need Dr. Densen cited the Medicaid program. It is a financing mechanism to provide funds for medical care of the indigent. It is an insurance mechanism that happens to have a denominator. But it is not so much a welfare program as a social program, and as such "conceptualization of the statistical re-

quirement should be approached on the basis that it possesses certain epidemiological characteristics." We should be able to get information from Medicaid and Blue Cross of the kind that comes from New York's Health Insurance Plan. Not always can they tell us how many people they have in their programs, as distinct from the number of contracts they have written. This also is true of most commercial insurance companies. Dr. Densen suggested that if the need to conceptualize problems was strongly emphasized, it would not be necessary to train people to be welfare statisticians, health statisticians, and so on.

Again, in computerizing we need more conceptualization. One of the difficulties in health care programs is that people want to collect and cross-classify everything. "The computer can be very inflexible in some kinds of situations." What information do we want? If you mix what administrators need to know on a day-to-day basis with what is needed for research, you get a complex statistical system that does not answer the research questions and interferes with the administrative questions. We need in fact to examine the nature of reporting systems as such:

*I have my own bias toward collecting as little as I can get by with to run the system on a routine basis, and set things up flexibly so that it is easier to get additional data or make changes in the statistical system when they are needed.*

There are even systems where the physicians must spend so much time on their records that it interferes with taking care of their patients; and there is at least one jurisdiction in the Boston area where a pregnant woman must go to four different addresses in filling out her financial eligibility forms. We need to think throughout in terms of the total system, in relation to all who are involved, including of course the research statistician. "You need a good system as well as good people to operate the system."

Dr. Densen had one question concerning Dr. Linder's presentation. He had reason recently to go back to the Shattuck report and was struck by the fact that Shattuck strongly emphasizes the link between the statistics and service programs:

*I can see your concern to attain objectivity. Perhaps at the Federal level and even at State and local levels you need an agency with this characteristic. But if you get too far away from the operating programs, you may begin to concern yourself with unrealistic things. At the local level particularly we need to relate our statistical activities to the service programs of the community. We must not get ourselves into the position of thinking that we are collecting statistics for their own sake, especially in the health field. If something is not done to relate the statistics to action directed to improving the health of the population, I fear greatly for the statistical profession.*

Take the statistics that the National Center is gathering on the country's smoking habits. They show that a smaller proportion of the population is smoking and that the age at which people start smoking is changing. Can it be said that this has resulted from the activities of the Public Health Service and other health agencies? At present one cannot say this. But it is important that the question be studied. Or take infant mortality. This certainly is a field where we have lots of information;

*But in a situation where the Negro rate is say twice the white rate and you are supposed to do something, you are stuck at the present time. Here we may need to go to microstatistics and follow up the individual circumstances that surround individual deaths.*

At the present time, as Dr. Linder noted, we do not have the statistical talent or know-how at the local level. We do have it at the National level and in the universities—not necessarily in the schools of public health. This talent should be made available in an effective way to operating agencies and communities.

One place of quick return for a relatively small investment is in summer programs for college students. "It galls me to find that the Federal Government just will not put any money into this area."

In the general discussion, Dr. Hauser agreed that the Federal statistical system needs restructuring. He advocated "the equivalent of a central statistical agency in the government, removed

from all departments and as part of the Office of the President." Dr. Hauser also agreed with Dr. Linder's strictures on training, but thought that this was a part of the general university situation in relation to Federal funds. "There has been too much Federal money for specific purposes with strings attached, whether contract or grant, that have distorted training programs."

With respect to small-area studies, family data, longitudinal studies and the data bank, Dr. Hauser agreed that some are using these techniques irresponsibly, but thought that this was not a good reason for throwing them away. Of course there are the difficulties that Dr. Linder emphasized; we need to address ourselves to their solution. For example,

*The type of analysis which demographers have developed in terms of the cohort analysis of fertility data is badly needed elsewhere and readily extensible to other forms of data. We need information that follows specific cohorts, not only with respect to their fertility experience but in relation to their educational experience, their entrance into the labor force and their vocational careers, and on down the line through health, welfare, and social security.*

"Our job is not to despair in the face of such problems, but to develop techniques for their analysis."

Mr. Woolsey found himself pleased that his long working career of arguing with Dr. Linder was not going to stop. On the question of small area data needs, he found the disagreement "really quite sharp."

*To keep statistics from becoming dead, we have to keep them attuned to the problems of today. Today we just cannot overlook the need for data to delineate and overcome the problems of the cities. If we neglect these problems, we might as well forget about our statistical systems. They will never get the support of the Federal Government.*

So far as the vital statistics system is concerned, this means that we cannot go to a sample basis at the present time. Here we have one of the very few means for getting measures of health in the cities, including their ghettos and their disadvantaged people.

It is true that a lot of poor work has been done in the area of family statistics. When we get into the health economics, where families are spending units, however, there is something that can be handled.

Longitudinal studies are often engaged in needlessly, and they are undeniably difficult. But there are some questions that cannot be answered otherwise, as when one needs to discover the outcome of a certain course of events.

On data banks, Mr. Woolsey was in full agreement with Dr. Linder and would go even further:

*The two basic defects of the data bank have nothing to do with confidentiality or the invasion of privacy. One is that it is a very inefficient way of producing and disseminating statistical information and is unfair as a means of disseminating the information. Some of the information will be controversial, and because of cost considerations, will be available only to the well-heeled.*

*The other defect is that you would have to deoptimize the individual systems to get the degree of record linkage that is proposed. These systems were designed to serve particular purposes, for which their classifications were established. You would have to change this to get the records linked.*

With respect to training, Mr. Woolsey thought that most would agree that training in health statistics has been largely shaped by the influence of money from the National Institutes of Health (NIH).

With respect to the location of a central health statistical agency—say the 'Center—there are subtle problems connected with location in an agency with a mission. "Nevertheless, I think we have been relatively free from interference." Mr. Woolsey thought one should balance the quality and integrity of the data, which are extremely important, against responsiveness to the needs of users.

*I think we have become more relevant since we have been located in the Public Health Service in the Department of Health, Education, and Welfare than we were before. Also in the experience of at least some of the countries, there have been serious difficulties where there was a central statistical office.*

Dr. Dunn interpreted Dr. Linder's specific comments on small area statistics and so on as suggestions that we should take a good hard look at these things. He would agree; but to make a quantum jump over the next 10 years Dr. Dunn thought we should apply ourselves substantially to developing indices of health. There are, of course, indicators of pathological conditions. We also need to quantify wellness. The National Committee took three study subcommittees to come up with the plan for the National Health Survey. Two of its subcommittees tried to define wellness and never came up with an answer. Perhaps a third committee could do better.

Dr. Klarman thought that the experience in reorganization of the Public Health Service over the last few years should serve as an object lesson. "Don't change the machinery unless you know what you're doing, and then hesitate."

He agreed that we need to conceptualize, but held that there can be great differences in where we can go when we engage in the process. Dr. Densen had stated that the basic problem statistically with respect to Medicaid lay in identifying the denominator. But the statistician also needs to know a great deal about the special, unique characteristics of the problem area and the institutional arrangements that make a difference.

*The number of people who turn out to receive health services depends very much on local history, local tradition, what people are accustomed to getting, what government will give them with some ease, and so on. When we get new notions of what are people's rights, we can get marked discontinuities. There was no basis for getting a good estimate of the size and characteristics of the population that would be using Medicaid.*

When different people conceptualize, they may reach different concepts, Dr. Klarman concluded.

Dr. Densen said that he would have a hard time disagreeing with that. But instead of discussing techniques and methodologies in general, he would prefer to sit down and talk over these different understandings.

Mr. Reed found advantages in using the legal process of registration as a carrier of statistical information. Nevertheless the United Kingdom is experimenting with a medical register of births to be used to initiate medical services, which

will go to the medical officer in most areas, and then to the central statistical agency. This appears to be similar to what was being proposed at this conference.

A strong school of thought in the United Kingdom favors an extension of medical record linkages, including such records as hospital inpatient records and first marriage and death records. At present the records would be linked only on demand.

Mr. Reed felt that the statistical agency should be independent "to preserve its statistical virginity against the politicians."

Mrs. Shackelford commented that the American Association for Vital Records and Public Health Statistics well recognizes that the vital statistics system is in trouble. It does not meet the extra needs and demands that are being placed on it by the new health programs and the new concepts that have arisen over the last few years.

*A lot of us—and I identify myself with this group—feel that people are expecting to make more sophisticated uses of the vital data without giving enough attention to maintaining the quality of the data, or to improving the quality and modernizing the system so it can more adequately serve today's needs.*

Mrs. Shackelford added that the National Committee should "devote some attention to what we might call the plight of the vital statistics system in many of the States."

Dr. Pirc testified that there was a deterioration of the statistical activity in Yugoslavia when it was located in the central statistical agency. The health agency needs the statistical agency every day.

Dr. Thompson felt pessimistic about developing strong health statistics training exclusively in a university setting. A university can teach mathematics and biology and other long-existing subjects, *but not problem solving*. And it is probably wrong to suppose it should try. "If you want to teach someone how to do something, the best way is to start them doing it." Perhaps the training might involve both the university and a community hospital or other health agency. Students need to face real problems, and not the artificial, synthetic kinds of things they meet in schools of public health or medical schools.

Dr. Baehr observed that some schools are beginning to concern themselves with demonstrations in medical care, using a population laboratory as a basis for training. These are open to physicians and others, including statisticians.

Dr. Kiser noted that the National Committee has a subcommittee on vital statistics revision under the chairmanship of Dr. Lee. It has decided to start from scratch, taking all aspects of the existing system into account.

In some final remarks, Dr. Linder stated that what he was recommending was a more critical examination of certain techniques that have almost become catchwords, and also a critical examination of the vital statistics system as a statistical collecting mechanism.

*If you want a horse and buggy, we have got a horse and buggy, and I do not think you need to attach a jet engine onto it. I was saying, is that what we want at all? Can we depend any longer on this slow and outmoded and very restricted system that exists largely for legal purposes?*

## Needs in Health Services Resources and Utilization Data

### PRESENTATION BY DR. KLARMAN

Dr. Klarman considered in turn data needed for internal management, research, and planning, steering a course between asking for everything and asking for too little. He did, however, lean toward restraint. He gave more attention to the data needed for planning, since needs in the other two areas are likely to be special and unique; neither problem lends itself at present to widespread data collection on a routine basis.

For internal management one needs a budget in money terms and a program of operations expressed in inputs and outputs. At this point the latter are units of service, not end results. Departmental costs may be compared over time; total expenditures with budgeted expenditures; average unit costs with those of other institutions; et cetera. Frequently data compiled by several institutions for internal management can be usefully combined.

Planning is an obvious ingredient of internal management so far as each single institution is concerned; but area-wide planning is not simply the sum of the plans of individual institutions.

In research we have needs that may be distinct from those of management and planning:

*In research, data needs are set by the problem under study—by the hypotheses to be tested and the variables of a model that appear to offer a plausible picture and explanation of real life behavior. Actually, however, data collected for management uses sometime serve as proxies for the research data needed.*

Research needs depend not only on the problem under investigation, but on the approach. Thus economists and political scientists are not likely to ask the same questions about a problem.

There are two major problems in applied health services research today:

*These are the marked acceleration in medical care costs—perhaps expenditures would be the more precise term—over recent years, and the urgent need to bring health care to the urban poor.*

Many studies could be set down under each of these problems, but a listing of studies would not give us a listing of research data needs. In addition to the different questions that would be posed by the several disciplines,

*Data needs are specific not only to the problem and not only to the questions asked about it, but also to the particular model to be tested, which in turn depends in part on the findings of earlier research.*

Difficulties in specifying data needs multiply as research moves from the applied to more basic areas of concern.

*This would include most studies of the end results achieved from health services programs, as well as studies directed toward formulating priorities between health and other social goals, as likewise between health services and other inputs for promoting better health.*

Dr. Klarman now turned to data for planning, where more generalization is feasible, and therefore more routine data collection. Here he proposed to apply the test of relevance: "If these data are collected, what are they good for? How would you use the data if you had them?"

Typical planning reports in the health field include data on population size; age composition; births and deaths; a count of facilities and key health personnel; projections of population and requirements. Also likely to be included are use data by location; per capita use of services; the population's income and educational levels; and (in recent years) its mortality and morbidity by diagnostic category.

*Yet no explicit connections are drawn between the data and the policy recommendations. The very presentation of the data is assumed to suggest their germaneness, as if the connection was self-evident.*

Dr. Klarman questioned whether all these data—"and more"—are needed in planning future health services. Before seeking to determine what data are required, we should dispose of three preliminaries: choosing a criterion for planning; arriving at a functional model of the health situation in the light of our criterion; taking account of the implications for planning of uncertainty concerning future population changes, preferences for services, and the supply of specialized factors of production. He discussed each of these matters in some detail.

*Choice of criterion.*—The need criterion is usually espoused by health planners, while economists generally favor the demand criterion.

*Health professionals assume that they know and can state with some precision what services a population should have. It then remains only to surmount the financial barrier to achieve the indicated types and volumes of services.*

Lee and Jones developed well-known techniques for translating pathological occurrences into quantities of services and for converting these into manhour requirements, which then are turned into full-time equivalents in terms of the length of the work week.

*The professional judgment is intended to reflect the biological needs of the population and the current technological capabilities of medicine. It explicitly disregards economic factors and also takes no account of psychological awareness or appreciation of the value of services.*

*Among other consequences, it is implicitly assumed that health services can claim an absolute priority on resources; that they always combine in the same way with other services to produce health; that the various resources combine to produce health services according to the personnel-to-population ratios; and that socioeconomic status has no bearing on the taste for or desirability of using health services.*

In Dr. Klarman's judgment these assumptions are questionable, and therefore "need is not a proper basis for health planning, so there is no point in meeting the data requirements it implies."

The demand for health service is a functional relationship between quantities of services supplied at certain prices, which may vary according to the prices of other products, incomes, and the tastes and preferences of the population as stemming from its demographic composition. "In the real world, however, purchasing power is not located only in consumers. Government too can manifest demand by deciding to pay for something." The demand criterion is more realistic than the need criterion:

*The problems which are overlooked by the criterion of need are the presence of socioeconomic factors in utilizing services and recognition of the diverse elements that enter into decisions. When government participates, these can be taken into account.*

**Choice of an explanatory model.**—In addition to a multitude of possible variations in use patterns, there can be many variations in the way services are provided, according to forms of organization, productivity, scale of operation, et cetera. Also possible are detailed differences in value judgments based, e.g., where equality is the goal, on equal access, equal use, or equal health status.

This procedure, however, has one serious difficulty at least for the time being:

*In one area of hospital use where an effort has been made to compare the explanatory power of several models, it was found that the naive model which projects present use accounts for the larger fraction of total variance in utilization.*

Dr. Klarman's conclusion from this analysis was that the most useful data for planning are:

1. Rates of use by the several population categories under various conditions of financing and organizing the delivery of health services; and
2. Projections of specialized facilities and manpower under explicitly stated alternative assumptions.

He left specification of the population categories and resources to be projected for further discussion.

In the hospital field, there is the further complication that the level of supply strongly influences the demand for services. "In the absence of any observed ill effect on health status, this means that almost any level of hospital supply within the known range is a valid level. "Perhaps here the appropriate basis for planning "is some measure of equality—equality of access to services or of use—within the particular community."

**The uncertain future.**—Health service plans typically look 10 to 15 years ahead. A longer period would greatly increase the already considerable uncertainty. The chief difficulty is population size, especially as respects the small areas for which most health services are provided. Birth rates and migration patterns vary unexpectedly. Since more accurate projections can be made for large populations than for small ones, where resources are mobile it might be advisable to project requirements and availabilities for the size of area that can be regarded as a single market. Planning areas will differ in size for various resources, being smaller for immobile ones, such as fixed facilities. On the average it is more economical to combine resources in an adaptable fashion, having facilities operate at a constant—

though higher—cost over a considerable range of output.

*It strikes me that for planning purposes the foremost need may be a data bank of tested ideas in the flexible use of resources, given the uncertainties surrounding projections of population, in medical technology, and in a population's desires for health services. For this reason alone a comprehensive approach to health services organization is preferable to a categorical one in which services are segregated.*

## Discussion

The assigned discussant, Dr. Anderson, agreed in general with Dr. Klarman. The bane of the health field is too much data. "We are victims of tremendous data-gathering machines and tend to be intellectually lazy and asphyxiated when it comes to design."

We have a variety of health delivery systems, in this country and abroad. They are all obviously functioning in some way or other, but we are barely at the beginning in finding out how they actually do work. We are still largely in the structural or static descriptive stage. We are far from achieving measurements of efficiency. "We cannot even decide what are outputs and what are inputs. Use is an output in some of our models, instead of end results."

We are left studying such things as convenience, waiting time, equal access, and so on. "We do not know what proper use, or proper balance in uses, may be. "We can take various delivery systems and show what they cost, how convenient or inconvenient they are, and "very, very roughly" some of the quality levels.

*The health service system is, then, an end in itself. It relieves pain, reduces anxiety, and occasionally saves life. I really think this is a very sophisticated outlook. With backward populations, you can change things by health services. The leading cause of death is an excellent measure of good health care. If it is heart disease, you are getting good care.*

When the discussion was opened to the group, there was some consideration of utilization as a

measure of health services. Dr. Sagen referred to the multinational study of health service utilization involving Finland, Poland, Yugoslavia, the United Kingdom, Argentina, three provinces in Canada, and two places in the United States. The study strengthens the view that we have no good notion of need. At best we have only data on the degree to which needs are perceived. Thus in Yugoslavia the rural agricultural population used the services less often, and yet when services were used they stayed for longer periods of time. Dr. Densen commented that this is true also in the United States. It has been suggested that some groups find it easier to stay in the hospital, since they do not have anybody to take care of them at home.

Dr. Densen also held that a functional approach would prove helpful, in addition to morbidity and mortality. "An activity framework is needed." This was reinforced by Dr. Krohn:

*The disclosure of unmet needs is a very difficult problem, especially in cities with old people—down to ingrown toenails that may lead to severe problems. Almost anything may come to light when a population is examined in some detail.*

Dr. Berg also thought there was need for a diagnosis of function, just as of disease. "We also need to understand how the public views dysfunctions—even doctors often have very different views."

Further discussion developed the thought that, while demand may be better than the need model, end results are also of some use. There is also a fourth possibility—identification of problems and measuring degrees of result. It was also noted that the meeting had confined itself almost entirely to curative services, although they are only one part of the model. In addition there are environmental health services, nutrition, housing, employment, et cetera. "We need a model of all health services." Mr. McNerney also mentioned the varying demands of the individual, the employer, the neighborhood, the country, and so on. And Dr. Pirc pointed out that demands can change overnight. In Yugoslavia, demand tripled after passage of an insurance law.

# Needs in Demographic Statistics

## PRESENTATION BY DR. HAUSER

Dr. Hauser confined himself to considering future needs for demographic statistics only insofar as the United States is concerned.

*Population totals.*—During the 1960-70 intercensal period current population estimates and projections for standard metropolitan statistical areas have been developed. These data will make it easier to apply what we know about the country as a whole to these areas. We also need similar information for much smaller areas, including subdivisions of cities and counties, and especially community areas, which often do not conform to political boundaries.

*Population characteristics.*—We need similar information for such population characteristics as age, sex, color, and socioeconomic status (such things as income, education, occupation, social mobility). The education of decedents, for example, is a much better index of their socioeconomic level than their last year's income.

*Fertility measures.*—There will be a new baby boom in the immediate future as our postwar babies increasingly enter their reproductive years.

*It would have begun earlier except that age at marriage and age of having a first child increased. I think this is because our present young cohorts are learning that our society and economy are just not able to change rapidly enough—in this case expand—to accommodate to the changes in the reproductive pattern of the population.*

Yet the fact that the number of women between 20 and 30 years of age will increase about 35 percent within a seven- or eight-year period is certain to bring a new tidal wave of babies as an echo of the postwar baby boom.

Hence there is an urgent need for cohort data with respect to marriage, childbearing, child-spacing, and attitudinal data to throw light on what actually is going on and the motivations and incentives that are involved. This means that we need the equivalent of the Growth of American Family studies on an annual basis. We need to be kept up to date concerning knowledge, attitudes,

and practices with respect to family formation. What we need are parallel period and cohort fertility data, including nuptiality rates and fertility by parity and age.

In a recent book<sup>1</sup> published by the University of Michigan, Dr. Noman Ryder has constructed a complete bridge between period and cohort fertility. He found for the United States over recent decades that about two-fifths of the variation in period fertility was accounted for by the tempo of fertility as distinct from the quantity of fertility—that is by age at marriage and age of childbearing, rather than by changes in the number of children ever born. Thus tempo of fertility is an important component of population projections and should be regularly measured.

Also needed is the kind of information that can be obtained from pregnancy histories.

*Mortality and morbidity.*—For worthwhile reductions in mortality in the United States from now on, we are going to have to depend much more on what Dr. Hauser called socioeconomic epidemiology rather than on biomedical epidemiology.

*The differentials in mortality by socioeconomic status within the United States are tremendous. Thus for 1960, 29 percent of all female mortality in the United States would be defined as excess, using the female population having one or more years of college education as a socioeconomic index. The excess is about 9 percent for males.*

Some of the differentials by cause are quite startling, being of the order of 100 percent.

In mortality as in fertility we need cohort measures completely paralleling period measures.

*It is going to be increasingly meaningful to think in terms of cohort experience, and this too not merely in terms of the kinds of period measurements we now have. This will be true, for example, with respect to new biomedical developments, as with the antibiotics and estrogens. In fertility planning, cohort experience may be required to understand the impact of some modern therapies over time.*

<sup>1</sup>Behrman, S. J., Corsa, L., Jr., and Freedman, R. (editors): *Fertility and Family Planning: A World View*. Ann Arbor, University of Michigan Press. 1969.



*Internal migration.*—Needed will be current estimates or components of all the recommended estimates of total population including small areas and even their subareas.

*Marriage and divorce.*—The United States is far behind the rest of the developed world in marriage and divorce statistics. Improvement of the statistics in these areas would also help to improve fertility statistics. We need information on the duration of marriages by the number of the marriage, in view of our current "chronological polygyny and polyandry."

*Family statistics.*—The household statistics now available in the United States are primitive and unprecise. The annual estimates "wobble," demonstrating that the data are unstable.

*The family is an analytical unit for fertility analysis, mortality analysis, and labor force analysis. I think the family as a unit within the next 10 or 15 years will be as important as the individual in statistical analysis. The family-cycle information pioneered by Glick is now a standard apparatus.*

Here as everywhere in social analysis, longitudinal analysis should accompany period analysis.

*Mechanisms for achieving these goals.*—To get the statistics we need, among other things we must find ways of conducting the sorts of studies that Dr. Linder questioned—studies of small areas, family statistics, longitudinal studies, and linking records by data banks. Dr. Hauser agreed that Dr. Linder's criticism of the techniques now available was well-founded. He also agreed with Mr. Woolsey's criticism of data banks as he had described them.

*I could not agree more with Ted's objections—and even emotional objections—to data banks. But I think this Conference has illustrated that we keep using the same words with quite different images in our minds. In my data bank, I would not put everything onto the tape and then link everything with everything.*

*You would link those things for which you have a concept, a use, and a purpose. Even a multipurpose agency should never get information for its own sake. It gets data with explicit or implicit uses in mind.*

Linkages of already existing well-established systems—census, social security, internal revenue, NCHS—would greatly expand our statistical stores. The quinquennial census would also be helpful. In addition, Dr. Hauser revived a proposal for an annual sample census that he had made in 1941. It should be of adequate size to permit estimates for regions and possibly the metropolitan areas "and so on." Already the Office of Economic Opportunity has furnished resources that have enabled the census greatly to enrich its current population survey sample.

*There could be a series of sample surveys which are rotated during the course of the year, giving current information with the sample thickened or thinned as needed to handle current needs. A rotating sample giving local area information could be pooled to furnish annual statistics, much on the order of the National Health Survey sample.*

## Discussion

Dr. Lee, the assigned discussant, indicated that striking evidence of the awkwardness of the vital statistics system can be seen in the fact that the study of socioeconomic differentials in mortality that Dr. Hauser has been working on will not be published until 1970 (through no fault of his own) although it is based on 1960 data. A quinquennial census, although not yet achieved, was first proposed by U.S. Grant nearly a hundred years ago. "Both the vital statistics system and the census system in this country, though admirable in so many respects are antiquated."

*It is a shame that these two activities are so far away from each other. Since we cannot possibly foresee all the needs for data which will come over the next few decades—the political changes, changes in welfare and in population movements, for example—what we must try to work toward is a joint system of data collection. Perhaps the two activities need not be in the same agency.*

Even today we do not really have a continuing Census organization, although we do have continuity in the higher ranks. Every 10 years we hire another bunch of amateurs to do the basic work.

We do not really need to collect everything on a routine basis, much less tabulate or publish everything. There are some basic variables which are absolutely essential for almost any kind of analysis.

*You could almost say that age, sex, and in our country race, are always important, along with some good measure of socioeconomic status, preferably education.*

*For these we need a large sample, though not necessarily 100 percent, taken at quite regular intervals. Then we need to be able to choose a smaller sample from our list of respondents, to which we can put additional questions shaped in terms of immediately present needs.*

*We also need a vital statistics system which can be referred back to very quickly for further data. We do not need a vast amount of official data, but the ability to query the family, say, in which the event occurred. To do this will require a considerable restructuring of the vital statistics collection system, which should be undertaken in collaboration or cooperation with, or simultaneously with the census changes I have described.*

For a particular reason, for example, we might on one occasion collect considerably more information on every Aleut birth, and yet be content with, say, a 1-percent sample of other parts of the population. To get such a system and make it work, both a considerable decentralization of our census and vital statistics programs would be needed, along with a considerable central coordination.

Dr. Puffer endorsed the importance of paying more attention to multiple causes as a means of modernizing mortality statistics. She described a 12-city international research on mortality which shows that additional information from hospital and autopsy records when combined with clinical data enables more precise definition of

the cause of death. In another international study of the mortality of children under five years of age, in certain countries where nutritional deficiency was identified as the underlying cause of death in about 10 percent of the deaths, it was named as an associated cause in from 40 to 70 percent of the deaths.

Dr. Puffer was certain that modernization of the mortality statistics would provide important contributions to epidemiological studies of diseases, to knowledge of health conditions, and to our understanding of the bearing of socioeconomic factors on health.

Dr. Linder noted that he was "not too far apart from Dr. Hauser on one point," once a matter of definition is straightened out. His own scepticism as to the value of longitudinal studies applied to the followup of specific individuals, and not to the broader study of a group or "cohort" of individuals over time.

The need to pin ourselves down in communication certainly applies in the data bank area. Dr. Hauser had said that he wanted a data bank serving only specifically defined purposes, but Dr. Linder thought his example implied a vast multipurpose collection of data:

*I was agreeing with him wholeheartedly, and then his example unconvinced me. Into his data bank he was going to put the census (200,000,000 records); social security data (say 100,000,000 records); the internal revenue documentation (80,000,000, records, I would guess); and then he would add the Health Interview Survey. Out of all these records, he said we could get, for example, some better estimates of small area statistics and some information on internal migration. If you are after this, do not bother with the Health Interview Survey—there is nothing there with any bearing on this subject. Is there really much that you could pull out in all the other records on these two matters?*

*Contrast this with his other example of a continuous rotating, expanding-contracting, flexible sample to give information on metropolitan areas. One (the data bank) is an enormous thing involving hundreds of millions of records, from which it is doubtful that you could get much worthwhile. The other is a flexible tool, an expanding tool that can be redesigned for one problem this year and for another problem next year. This illustrates the kind of direct, sharp, and refined tool that statisticians should work for.*

Dr. Hauser later replied that he had had samples of the various sorts of records he had named in mind, and not the entire files.

Mr. Woolsey agreed with Dr. Linder, and gave an illustration of the problems that would arise from merging bodies of information collected for different purposes.

*When the question of a Federal data bank arose, we were asked whether it would not be wonderful to link the information on disability obtained from the health interview with what social security gets. The problem is that the definitions are not the same, and for a very good reason. In the case of social security the definition was established by law, and is extremely complicated. I would defy anyone to take that definition and try to carry it out in an interview survey. It could not be done.*

Mr. Woolsey went on to say that while he was opposed to open-ended record-linkage arrangements, where masses of records are put into a system for all kinds of potential uses, he felt very differently about closed-end record-linkage arrangements, where information from different sets of records is combined because specific objectives have been set up. An example would be linking infant birth records with infant death records. "That's another matter entirely, and can produce valuable data."

Mr. Woolsey agreed with Dr. Lee that the vital registration system would have to be extensively revamped to use it regularly in followback studies. "It's a very clumsy tool because it takes so long to get the results out. And of course our samples have been very small."

Dr. Densen expressed the view that big area people had been talking about small area statistics at this Conference. When various parts of the Public Health Service had conducted local area studies, they were not viable mechanisms. "Their average life span has been pretty short."

*The kinds of thing they tried to gather in the small areas were not sufficiently related to the problems of the areas. If we are interested in demographic questions arising in small areas, we should associate them with program questions.*

Dr. Densen also was interested in the relationship between the National Health Survey and small area information. He felt, for example, that reasonably good estimates of the proportion of the population covered by health insurance in a small area could be obtained by adjusting the National Health Survey data in terms of the age-sex composition of the small area. Are there any other questions that could be answered in this manner?

In advance of Dr. Hauser's reply, Dr. Klarman advised, "Don't do it. I tried it once." Dr. Hauser agreed:

*When you use the characteristics of an area, even a very small area, and attribute them to the persons living in that area, you are subject to the error of ecological correlation.*

The work of Victor Fuchs, who claimed that higher death rates were associated with higher incomes, had been mentioned as contradicting the Hauser-Kitagawa finding of an inverse relationship. Dr. Hauser stated that Fuchs' study illustrates the error of ecological correlation. His analytic units are entire States, of which many are extremely heterogeneous. The Hauser-Kitagawa differential mortality study will include direct measurements of the ecological correlation error obtained by comparing attributes of the individual as reported in the Census and on his death certificate with the same attributes as they characterize the Census tract in which he resided.

Dr. Sagen noted that vital statistics is full of small area statistics, "but we've got the wrong kind":

*Take Alpine County, California. I think it had 523 inhabitants in 1964. There were 2 marriages there in that year; 4 births to residents of the county, of which 2 occurred in the county; and 6 deaths to residents of the county, of which 2 occurred in the county. But we do not know anything about the Woodlawn District in Chicago, which may have say 200,000 people.*

Dr. Hauser agreed that our geographic classification system is a fundamental problem, "and we haven't done anything about it." About 1940 we were being promised a grid system, and now we have the zip code, but that is guided by postal convenience.

*We are not going to get very far with small area statistics or any kind of statistics on an area basis until we come to some better method of classifying areas and a method whereby individuals can identify the area to which they belong. I do not know what my census tract is.*

To a question as to the value of family-size-preference data, Dr. Hauser felt that these figures had not been adequately tested as to reliability or precision. They are nonsensical when used in developing regions, where everybody *knows* that God determines the number of babies you will have. When you come to Western societies, however, the technique becomes more meaningful.

*In a society in which fertility is almost 100 percent controlled, as is true of American society, it may turn out to be a pretty good indicator, just as it has been in American agriculture. "Intention to plant" was the source of Whelpton's family-size-preference concept.*

As a general observation connected with a number of matters touched on in the discussion, Dr. Hauser felt that more unified statistical cooperation, at the Federal level and between Federal, State, and local levels, might well be the quantum jump in statistics that would characterize the 1970's. But at the present time the country is caught in a system of State and local governments that is no longer meaningful.

With respect to a question concerning occupation as an analytic tool, it can be made to work very well indeed, Dr. Hauser stated, if income and education are included as factors. On a more general basis, it is rather poor. "Proprietor," for example, may include the fellow who owns a large sales enterprise and the chap who sells peanuts on the street corner.

With respect to education as a socioeconomic indicator, measurements are needed as to quality as well as quantity. In the 1970 Census we are going to find that nonwhite persons have just about caught up with white in years of schooling completed. Actually what this means is that in many of our local school systems, largely because of financial considerations, virtually no one ever fails.

# HEALTH DATA NEEDS AND USES IN FORMULATING PUBLIC POLICY

## PRESENTATION BY DR. RIVLIN

This topic was treated in a paper by Dr. Rivlin at a dinner meeting of the Conference. As Assistant Secretary for Planning and Evaluation in the Department of Health, Education, and Welfare, Dr. Rivlin had supervised preparation of "Toward a Social Report" (January 1969), which had been developed to fulfill a charge to Secretary Gardner in President Johnson's Health and Education Message of March 1, 1966:

*Through the programs entrusted to its care, the Department of Health, Education, and Welfare exercises continuing concern for the social well-being of all our people. Already, as I have indicated in this message, it has become possible to set ambitious goals for the future.*

*To improve our ability to chart our progress, I have asked the Secretary to establish within his Office the resources to develop the necessary social statistics and indicators to supplement those prepared by the Bureau of Labor Statistics and the Council of Economic Advisers. With these yardsticks, we can better measure the distance we have come and plan for the way ahead.*

In "Toward a Social Report," a social indicator is defined as

*a statistic of direct normative interest which facilitates concise, comprehensive, and balanced judgments about the condition of major aspects of a society. It is in all cases a direct measure of welfare.... Thus statistics on the number of doctors or policemen could not be social indicators, whereas figures on health or crime rates could be.*

Chapter I of the Report, on health and illness, was addressed to the question "Are we becoming healthier?" It was noted that the dramatic increases in our health and life expectancy that have characterized the 20th century have largely resulted from developments whose immediate effect

was on the younger age groups, and that the improvement had slowed down by the early 1950's. Further, the gains are very unevenly distributed among Americans, and at least 15 nations have a longer life expectancy at birth than we do. Among factors contributing to the country's failure to improve its health further, mention was made of

*styles of life (smoking, overeating, etc.)... socioeconomic deprivation... the uneven distribution of medical care, the relative under-use of preventive, as opposed to curative and ameliorative care.*

In her dinner presentation, Dr. Rivlin told the Conference that this health chapter had been the easiest to write. The study group that worked on the report had been able to find no data of comparable scope or quality for the other chapters. In the health area, statistics were available both as included on vital records generated principally for other purposes and as especially collected to yield health information. Of a third kind of statistics, experimental results—by which Dr. Rivlin meant the result of actual trials of hypotheses in real-life environments—"we don't have much in any area." Dr. Rivlin noted that even the health chapter was largely given over to negatives of health—to death, sickness, disability, and the like—rather than to positive aspects of health, where factual information still is largely lacking.

Preparing the social report revealed that we have much more material for assessing questions and problems, and for identifying relations and trends than exists for defining needs. We probably have suitable methodologies but few data. When it comes to deciding on what action courses to follow, "the problems are horrendous.... We don't even have the mechanisms here." The variables are multiplied; we cannot be sure about where we should start; there are many competing needs and complicating factors; political considerations and vested interests may come to the center of the stage; methods of assessing results are obscure. Then when a great deal of money was put into education, a few years later it was diffi-

cult to say what had been obtained from the investment. In the social sphere, results may take shape only during the course of entire life histories, and may be expressed in terms of widely proliferating relationships for which measures are often uncertain or nonexistent. Further, there may not be very much difference, in the real world, between a social program and the alternatives that are proposed.

Dr. Rivlin asked, "Is there any good way to judge a social experiment except by trying it out in real life?" In any event, the difficulties and actualities seem to argue for less aggregated data, and more specific information focused on definite problem situations where real social experiments come under consideration.

## INTERNATIONAL COLLABORATION OF NATIONAL COMMITTEES

### PRESENTATION BY DR. SKRINJAR

The initial presentation was by Dr. Skrinjar. She had decided to cover the entire theme of international cooperation in health statistics, rather than merely in relation to National Committees on Vital and Health Statistics.

### Diversity of National Efforts in This Field

National vital and health statistics vary greatly in reliability, relevance, comparability, availability, and degree of use by health planners and decision makers. Very often the producers of the statistics, the statisticians who develop them, and their consumers are not working together sufficiently. Hence there is need at the international level to demonstrate the usefulness of cooperation. One way of doing this is by showing how useful cooperation between nations can be. This collaboration has taken different forms: exchange of information, including such things as data, practices, definitions, methodology; exchange of ideas on methodological and organizational questions, leading to international studies of various questions; and dissemination of the results, with assistance to countries to put them into practice.

Cause-of-death statistics have been the main area for activating international cooperation. Nevertheless, Expert Committees on Health Statistics, regional conferences, and other meetings have made recommendations on many topics, of which Dr. Skrinjar mentioned especially hospital statistics, for both administrative use and morbidity analysis; various types of morbidity statis-

tics, including diagnostic and measurement problems, sampling methods, and various analytic techniques; cancer statistics, including registries; and health service statistics, including resources, activities, utilization, special services, and measurement of the efficiency and effectiveness of services. Attention has been paid to other subjects, such as health statistics in developing areas, health indicators for measuring levels of living, problems of teaching and training, and of course the activities of National Committees on Vital and Health Statistics.

With the advent of modern methods of data handling, the old questions of how to improve the collection of information, the quality of the information gathered, and the utilization of the statistics have taken new forms. Without doubt a variety of answers are dictated by varying situations and resources. Record linkage and statistics obtained through ad hoc surveys are coming into more frequent use. Because of these and other changes more detailed training is needed by statisticians. This subject too has been considered by a number of Expert Committees.

The rapid social and technical changes of recent years have increased the need for coordination and collaboration in developing health statistics. Thus the WHO Regional Office for Africa is including a paper on "Collaboration in Health Statistics in Developing Countries" in its June Regional Seminar.

Essential to international cooperation in health statistics is cooperation at the national level. In many countries various departments and agencies have developed overlapping health statis-

tics. These need to be integrated to simplify the administrative system and make it easier for users to satisfy their needs, as well as in preparing general national plans.

### National Committees and Their Equivalents

Not all of the 50 National Committees on Vital and Health Statistics, or their equivalents, which have been created are currently active. Funds and personnel may have been lacking or there may have been no means of implementing Committee recommendations, or the statistical organization responsible for vital and health statistics may have failed to show interest.

The organizational patterns of National Committees are varied:

1. A Committee may function as a subcommittee of the National Council of Health, or of the National Council of Statistics.
2. A Committee may be organized as an interdependent or even independent inter-agency body, working through standing subcommittees or ad hoc appointed groups.
3. The Committee may be set up within the Ministry of Health to coordinate the work of various departments concerned with health statistics.
4. Two or more standing committees may be responsible for specific health statistics fields.

Some countries with a highly centralized statistical system have thought that a special coordinating and advisory body was not needed.

*In view of the evaluation study of National Committees that WHO is planning to make, and in connection with this anniversary Conference, WHO has contacted members of the WHO Advisory Panel on Health Statistics, and also has received comments from four Regional Offices, to get views on how coordination of vital and health statistics can best be achieved and the collaboration of national experts be improved. Replies from 40 offices were received.*

It is believed that a National Committee becomes possible in countries with developing statistical services only where a permanent advisor is assigned to a well-supported project. Even then, a health statistics committee cannot do much without strengthening the statistical unit, since otherwise there would hardly be any way to implement the recommendations it might make.

International collaboration of National Committees could take a number of forms:

1. National Committees could be one of the ways in which countries cooperate in international studies.
2. Neighboring countries could collaborate on problems of common interest.
3. Permanent or ad hoc cooperation in particular fields might be arranged.
4. National Committees could provide guidance and advice to similar agencies in other countries.
5. Information and other materials could be exchanged.

"To be of practical service, WHO must be guided, supported, and authorized by the countries concerned."

### Discussion

In the ensuing discussion Dr. Krohn remarked that the European Region, where he serves, displays problems in health and in health statistics very similar to those of the United States. "On my way to this Conference I thought about our problems, and not one of the points that occurred to me has not been mentioned here." The populations in his region show low levels of increase, with drifts toward the higher ages. "In such a population many of our health problems are not detectable by traditional statistical systems." The death statistics for the older ages, with large numbers of deaths in relatively few categories, are not very sensitive. Nor are the health problems very satisfactorily reflected in hospitalization data.

*But not all health statisticians are worried about this. Some have not felt that this is*

*their responsibility. In some countries their primary task is to gather data in agreement with the present rules, and the final goal in their efforts is an annual report along traditional lines that gets published 2 or 3 years after the events.*

Health administrators, however, are greatly concerned. "They need intelligence units which can rapidly provide current information of importance for administering health services." What seems to be needed are ad hoc surveys, possibly obtained by means of a rotating sample such as Dr. Hauser described.

But there is perhaps the more important and more difficult fact that we lack indices for measuring the kinds of morbidity we are now faced with.

*Consider for example our epidemic of traffic-accident injuries, particularly among young males. Why are they such a high-risk group? When they are examined, we find that they are at the peak of their physical development. They are in as good physical condition as they will ever be. There must be something else.*

*Again, especially in Scandinavia, we are facing an epidemic of psychotropic drug misuse. What is the population at risk? We cannot use the typical risk factor of poor socioeconomic condition because this kind of morbidity is found largely in well-to-do classes.*

Dr. Krohn concluded by advocating more flexibility in health statistics services and measures. "We can't just do more of the same. We must choose and innovate."

*We need something like what you have in the United States. Here in the National Center you have a unit which simply sits and analyzes situations to find out what they really mean. I think this is of tremendous importance, and is something we lack in European countries.*

General comparisons between countries based on routinely gathered statistics have been overplayed. What is needed is an interchange of methodologies. The National Center might well enlarge its distribution of methodological reports by soliciting the names of appropriate individuals. Re-

ports sent to government agencies sometimes end up on the shelves without having been read by those interested in and responsible for the subject in question.

Mr. Reed observed that the United Kingdom had had a National Committee which had done a tremendous amount of work, especially on the Eighth Revision; that it was presently without any National Committee at all; and that it would shortly have two such Committees working in parallel—on medical and on demographic statistics. The hope is that these will do a great deal of their work through ad hoc committees dealing with particular problems.

Mr. Reed felt that WHO was especially valuable, in relation to national activities in health statistics, because it acts as a catalyst. "It's easy at international gatherings to decide that something needs doing, but if someone from WHO does not take the initiative it may not get done." But there is also need for collaboration between individual countries, as had occurred between the United States and the United Kingdom on multiple causes of death.

Dr. Pirce noted that WHO's Expert Committees up to 1960 often mentioned National Committees, but since then almost not at all. In his judgment, he felt that this meeting should express the view that the work of National Committees should be more strongly emphasized. Dr. Dunn, chairman of the discussion, suggested that perhaps a letter from the Secretary of the U.S. National Committee noting this suggestion might be helpful.

Dr. de Groot was of the opinion that Segi's work on cancer in various countries shows that international comparability has its merits.

In view of special needs in the Netherlands, Dr. de Groot recommended development of special coding and classification systems for various medical specialties, and for the measurement of morbidity in general practice. In the latter area there has been some collaboration between Dutch and English organizations. Secondly, there is need to push for international comparability of categories for occupational and social groups. Methodological cooperation would be desirable in establishing international standards, more apt than the conventional ones, for the appraisal of health and social well-being. Cooperation with other countries would be helpful in relation to studies of the



geographic distribution of certain conditions, including congenital malformations of the central nervous system, in relation to stillbirth and infant mortality rates. Work in the Netherlands would be helped by comparisons with Germany, Switzerland, Belgium, and France.

Dr. Guidevaux reported that France's National Committee consists of representatives of most of the government agencies that are interested in health, and persons from various technical agencies providing or using health statistics. The French Committee has no executive authority, and limits itself to such areas as mortality, morbidity, and hospital statistics. She would welcome international comparisons through the good offices of the World Health Organization, and likewise through publications describing work being carried out in various countries.

Dr. Puffer reported that National Committees have had a varying success in individual Latin American countries. In addition regional advisory committees have sometimes proved useful. Dr. Puffer then asked

*Why is it that the present National Committee has had so much success? I think one of the reasons is that it has called for help from many specialties. Another reason is its choice of topics for study. And I think a third reason is the continuity of service and contributions of its Executive Secretary.*

Dr. Dunn then called on Dr. Moriyama, who spoke as follows:

*I agree with Dr. Pirce that WHO has not played an active role with regard to National Committees. I would like to see WHO exercise leadership in promoting National Committee activities.*

*The National Committees, many of them now inactive, have been in existence for the past*

*15 to 20 years. Perhaps it would be useful for each of the national committees to reexamine now its program and functions. In this connection, Dr. Skrinjar mentioned coordination as an important function of National Committees. While it is true that coordination is needed in many countries, the assumption of this function by National Committees may make it difficult to carry out the more important technical development activities that National Committees can usefully pursue.*

*Lastly, it may be desirable to hold another International Conference of National Committees to establish new goals for National Committees.*

Dr. Densen called attention to the fact that Dr. Skrinjar herself and a number of discussants touched on a common theme—the need to develop health statistics in relation to service programs. This could be one of the ways of vitalizing National Committees. It certainly could be one of the ways in which WHO could take some leadership.

Dr. Linder urged that a national conference of the present kind be arranged more often than every .5 years, with international participation.

Dr. Dunn referred to the World Health Organization's definition of health as a state of complete physical, mental, and social well-being.

*This is the most widely quoted definition in the health area that we have ever had; but no one really understands it. It is up to the statistical people to make what it means more real in terms of health entities consonant with the definition.*

Dr. Skrinjar reminded the group that WHO would be glad to help; but "WHO is there to give whatever assistance it is asked for. It cannot do anything without support at the national level."

## CONCLUSION — BROAD CONFERENCE THEMES

Dr. Berg commented on the general tenor and content of the Conference. He found "a remarkable degree of agreement on a number of methodological and philosophical topics; but what is remarkable, the views we agree on are not in fact shared by most vital statisticians or registrars or even epidemiologists." He identified four organizing principles that guided the Conference.

The first of these is "a remarkable degree of flexibility and imagination"

*With an emphasis on conceptualization and free-wheeling thinking about new ways of attacking data and their meaning. This can only happen, however, when one maintains continuing attention to definitions.... It was perfectly clear that we are going to have to define our terms carefully if we want to think freely. Even in the area of confidentiality and the right to privacy, it is clear we need to see more sharply what we are thinking of.... It was interesting that we even disagreed on terms like longitudinal, followback, and so on—classical terms of our profession. So too with comparability—it becomes possible only when we can agree on terms and methods.*

The second broad area of agreement is "the emphasis on relevance or discrimination":

*Rather than just going out and gathering masses of data and increasing our empires by the storage of tapes, everyone agreed that we must make definite decision as to what we do.... This willingness to insist on relevance and decision-making as an absolute basis for even the gathering of data, and the methods of developing data, shows a remarkable flexibility and freshness. We were even willing to consider abandoning the classic vital statistics system as a means of obtaining basic data.*

*The advantages of the emphasis on relevance are not only economy but quality. Even with respect to data banks and record linkage, it is evident that we agreed that this was not just an indiscriminating massing and com-*

*bining of data, but techniques to be judged by the quality and appropriateness of the material to be obtained. Perhaps too following this path will do much to bypass the threat of confidentiality breaches.*

The third broad area of agreement is related to what Dr. Dyar called "uncertainty":

*I would locate here all the emphasis on the need for methodological research and development so that we are not so uncertain as to what we are doing, and that we are less uncertain as to what sharing of personal information the public will tolerate.*

In the fourth place, Dr. Berg stated "we identified the broad issue of trusteeship":

*Who is going to be responsible for upholding the public's rights, whether they find expression on the one hand in the need to avoid invasion of privacy or violations of confidentiality, or on the other hand, in making certain that the statistical data serve well not only society in general but people?*

As a personal expression, he being an epidemiologist and not a vital statistician, Dr. Berg concluded:

*I want to give an enormous vote of confidence in the vital statistics interest. The vital statistics people want the information they are gathering to be not merely stored in books but used; and therefore they want this information to fit our growing needs.*

Mr. Woolsey thanked the National Committee's international visitors for their attendance and participation. Mr. Reed responded on their behalf. Dr. Berg noted that a generous contribution from the Milbank Memorial Fund had helped to pay part of the expenses of the meeting; and concluded it by expressing the thanks of the conferees to the staff—Mrs. Petersen, Mrs. Lane, and Mr. Krueger—who had contributed so much to the smoothness with which the Conference was planned and executed. At an earlier meeting, Dr. Moriyama had been presented with a plaque commemorating his 20 years of service with the National Committee.

## APPENDIX

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