The National Health Survey—in the Beginning

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TWENTY-FIVE YEARS AGO, on July 3, 1956, President Eisenhower signed into law the National Health Survey Act of the 84th Congress, and thereby made possible continuing national surveys of health.

The act begat a family of statistical systems, for the founders of the National Health Survey planned not just a single survey but "a program of surveys, using different approaches and having changing end objectives as both the techniques and the needs for data evolve" (*1*). From those varied data systems have come much of the current knowledge about health in the United States, condensed in a series of more than 600 reports issued since 1958.

Accumulated year by year, the "bits and pieces" that are statistics slowly formed a picture. Some pieces of the picture are still missing but, because of the National Health Survey, the nation has a better basis than ever before for assessing health needs and planning action.

On this 25th anniversary of the National Health Survey Act, it is appropriate to look back and to try to reconstruct what it was like in the beginning.

Background

In the mid-1950s national health data sources included the reporting system for communicable diseases and the death registration system. Various health programs produced data related to their activities. Data that were both recent and representative of the general health status of the population were not so readily available. Statisticians in the Public Health Service (PHS) and elsewhere still relied primarily on the National Health Survey of 1935–36 as the basis for estimating the current level of illness and disability in the United States. That survey, part of a comprehensive National Health Inventory, had covered 700,000 urban families in a study of health under the depressed economic conditions of the time. Directed by George St.J. Perrott of the PHS, the survey had been financed by the Works Project Administration as a health promoting project that also would create jobs for some of the unemployed.

In the 20 years since the survey the country and its people had changed. Between 1936 and 1956 the country had gone from Depression to war to recovery; its population had grown from 128 million to 168 million, increasingly urbanized. Medical care had advanced, and so had health. The tuberculosis death rate had dropped from 71 per 1,000 population in 1936 to 9 per 1,000 in 1956, and the infant mortality rate from 57 per 1,000 live births to 26.

Over the 20-year period, too, the science of survey methodology and population sampling had advanced. The Census Bureau had experimented with questions on morbidity and disability in its monthly labor force survey. In the late 1940s and early 1950s came a series of health surveys. Among them were the California Department of Health's study of interviewing methodology, conducted in San Jose; the studies of handicapping conditions carried out by Community Studies, Inc., of Kansas City, Mo., and the Commission on Chronic Illness's "unique first attempt" to combine results of health interviews with comprehensive medical examinations of a repre-

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sentative population (*1*). The Census Bureau had done much to make a science of household sampling and, with the Public Health Service, had provided advice to those carrying out local surveys.

More than one proposal for a new national health survey had been made. The one that eventually became the basis for the National Health Survey Act was the report, "Recommendations for the Collection of Data on the Distribution and Effects of Illness, Injuries, and Impairments in the United States" (*2*), prepared by the Subcommittee on the National Morbidity Survey of the U.S. National Committee on Vital and Health Statistics. The subcommittee was chaired by Dr. W. Thurber Fales, and its members were Dr. George F. Badger, William G. Cochran, Dr. Edward Holmes, Dr. Morton I. Levin, Dr. Eli Marks, and Theodore D. Woolsey.

The subcommittee drew the blueprint for the National Health Survey—the types of data to be collected, the statistical standards to be met, and the types of studies needed. The report was submitted to Dr. Leonard A. Scheele, Surgeon General of the Public Health Service, in 1953.

A proposal for a national health survey in the President's 1956 legislative package was sparked by the need of the Department of Health, Education, and Welfare (DHEW) for information related to vocational rehabilitation—the number of people eligible for it each year, the number who could benefit—and by discussions between Charles Lawrence, Program Analysis Officer in the Office of the Secretary, who wanted the data, and Woolsey, a member of the subcommittee and a statistician in the Division of Public Health Methods, who recognized the need for the survey.

On January 26, 1956, the President in his "Special Message on the Nation's Health Program" urged the Congress "to authorize the Public Health Service to secure periodically needed information on the incidence, duration, and effects of illness and disability in the Nation."

Specially designed mobile examination centers were equipped with X-ray and laboratory facilities, soundproof booth for hearing tests, and other special features needed to assure high quality data

Once started, the proposal moved quickly. Legislation for a National Morbidity Survey was introduced, drew bipartisan support, and moved through hearings without memorable controversy. Along the way, the House of Representatives made three changes in the proposed legislation. It changed the title of the bill to National Health Survey Act, rendering its purpose understandable to the people who would be asked to provide information for it. The House also added a provision for the study of statistical methods and survey techniques, seeking continuing improvement, and it authorized the Surgeon General to make technical advice and assistance available on the application of statistical methods in health and medicine.

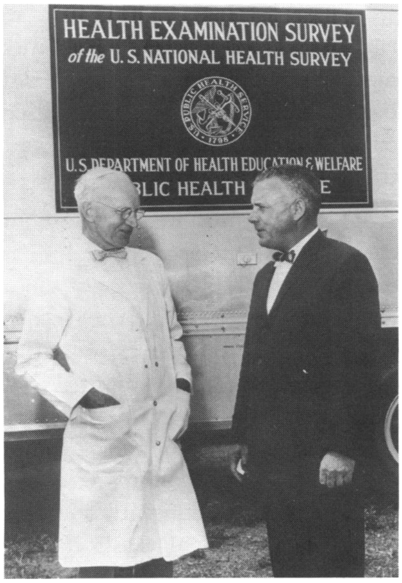
Six months after the health message, the National Health Survey Act was law. A year later, on July 1, 1957, the act's "continuing survey" began, carried out by interviewing in 36,000 households selected to be a representative sample of the civilian, noninstitutionalized population of the United States.

The first formal report of findings appeared in February 1958. It gave preliminary estimates, based on 3 months of interviewing, of the volume of physician visits in the United States (*3*).

Creating the Survey

Twenty-five years and some 900,000 household health interviews later, people who came early to the survey give great credit to their predecessors in the conduct of surveys and in population sampling. The National Health Survey staff were not a group starting from scratch. Much had been learned in the earlier surveys; much would be learned from the National Health Survey experience.

The new program was made a part of the Division of Public Health Methods. Forrest E. Linder was named director of the National



Dr. Carl Dauer, Survey medical officer, and the late Congressman John E. Fogarty of Rhode Island

Health Survey and Woolsey, assistant director. Walt R. Simmons, statistical advisor, Oswald K. Sagen, special studies, Philip S. Lawrence, household survey, and Alice M. Waterhouse, medical advisor, were senior program staff.

The act had authorized a three-part program: a continuing survey, special studies, and methodological studies. As the founders began to carry out the act, they defined their function and goals more precisely. The National Health Survey would not serve any single interest or meet needs for detailed local data. It would produce general data on the nation's health and show the various aspects in proportionate relationship to each other. Its unique responsibility would be the collection of the types of data which could be collected from a representative sample of the population or could be related to general population statistics (*1*).

Linder has written of the survey (*4*):

> When the National Health Survey was set up as a continuing activity, we soon decided that if we wanted to know about people's health, we would have to go to those people. Not even the most careful compiling and tabulating of data about people from physicians' or hospitals' case records would do. For one thing, such records have no standard content or level of detail. For another, any one person may seek care in the course of a year from a number of physicians, hospitals and clinics; their treatments of his conditions may overlap, and so will their records. Finally, even if all the technical difficulties could be corrected for, a major drawback would remain: medical records relate only to illness for which medical attention is sought, and there is a great deal of poor health that never comes to the attention of a physician or hospital.
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> Clearly the individual person is the only focus for all information about that person's life. It is only the individual himself who knows the total of his medical experiences: the illnesses, chronic conditions and injuries, the effect they have had on his life, and the places where he has sought treatment or preventive care.

The founders set other policies vital to a statistical program. They sought and received advice on needed data from inside and outside the Federal Government, particularly from the National Health Survey Advisory Committee. The staff strongly supported the study of statistical methods and survey techniques authorized by the act. Linder believed that criticism of your own data is the only way to make it better, and a substantial portion of the survey's budget went for methodological studies.

The act had authorized use of the Bureau of Census staff to conduct the household interviews for the survey, and a working relationship which continues was established soon after the act was passed.

Confidentiality was another immediate concern. Linder cites work toward the issuance of regulations by the Secretary of DHEW to protect the confidentiality of information reported in the survey as "the first thing I did." Legislation was later enacted to protect confidentiality.

For practical purposes, the household interview survey was the National Health Survey for several years. It began immediately, while the special studies authorized by the act were being developed.

Despite all their experience and the knowledge gained from earlier surveys, the National Health Survey's leaders still were not completely sure of what they would get. And believing that lay reporting of illness could not be translated to medical diagnosis, they chose to emphasize in the interview survey measurements of the effects of sickness and poor health on the individual as manifested in such ways as disability days and limitation of activity and mobility.

The National Health Survey's first questionnaire was modeled on the California health department questionnaire and ran to three 10½-by-16-inch pages. In addition to questions on acute and chronic conditions and impairments and their effects, it covered medical and dental care received, hospitalization, and the demographic characteristics of household members.

Robert Fuchsberg, one of the first statisticians with the survey and now director of the National Health Interview Survey, summed up the early attitude: "We put the best questionnaire we could come up with into the field in 1957, and then we set out to improve it. Data from those first years are not trends. We knew that there would be underreporting on some things and we were revising and rearranging the questions to improve reporting. It wasn't until the late 1960s that we felt we had a good core set of questions."

So the survey staff learned as they went along, through continuous appraisals of findings and methods. When estimates of hospitalization from the survey fell short of estimates based on hospitals' reporting to the American Hospital Association, they set up a study to find out why. Another study matched reporting of illness in interviews with medical records of those interviewed and the researchers found that there were inadequacies in records, just as in interviews. The staff began to appreciate the importance of people's perceptions of their health; a lot of conditions were not reported in interviews because the respondents did not think of themselves as sick. Moreover, some people failed to report conditions which they considered embarrassing even when the condition was life threatening.

Almost immediately, in response to special needs, the survey began to cover new subjects with supplementary questions—in 1959, questions on needs for home nursing care and use of aids such as wheelchairs; in 1960, on health insurance coverage; in 1961, on X-rays. What evolved over time was a questionnaire comprising a core of standard questions, repeated annually, and single-time and recurring supplements (*5*).

In 1963, in accordance with a long-range plan set out at the beginning, the survey staff undertook a full-scale evaluation of what by then was called the Health Interview Survey and began to experiment with changes which the evaluation of the survey seemed to indicate.

Reporting the Findings

The founders considered the entire health community, public and private, to be the survey's clientele, and publication of findings had high priority; several reports were issued based on 3 months of interviewing in the first year. To speed release and use of the data, those reports dealt with single topics. With a full year of data available, a series of reports was begun that covered specific population groups, such as children and veterans.

The goal for each report was a scientific work. Statistical findings were to be presented fairly and impartially, and publication of each set of findings would be accompanied by descriptions of data collection methods, definitions of terms, and other information that would help the users assess the reliability of the data.

Occasionally, this approach was misunderstood. Lawrence remembers one meeting where he was introduced as the representative of the survey whose reports "present such wonderful information and then carefully explain why the information isn't very good."

The original publication series, "Health Statistics from the U.S. National Health Survey," had four parts: one for program descriptions, one for findings by topic, one for findings for population groups, and one for developmental and evaluation reports. Each part was distinguished by a cover of a different color. That series gave way in 1963 to the Vital and Health Statistics Series of the National Center for Health Statistics.

The First Special Study

The National Health Survey Act authorized special studies as well as a continuing survey; the 1953 subcommittee report had called for special studies to complement the interview survey, including one "to obtain data on undiagnosed and nonmanifest disease."

There was no large-scale precedent for the Health Examination Survey that began in 1959 as a special study. In the early 1950s the Commission on Chronic Illness had examined a subsample of its interview sample in two locations, Baltimore, Md., and Hunterdon County, N.J. A national sample would require examinations in rural areas, small towns, and cities across the United States. Valid data would require standardized examination procedures and staff trained to follow them precisely.

In addition to questions about the desired content of the examination, there were questions about feasible content. Could heart disease be diagnosed in a one-time cardiovascular examination? What should be the criteria on glucose tolerance when people could not be asked to fast before examination? In consultation with scientists from the National Institutes of Health and other institutions, examination standards were developed and tested.

In the end, the founders of the National Health Survey took the very bold step of employing a traveling staff and mobile examination units that would move to areas in the sample. In the end, costs and sampling requirements precluded linking the examination sample to the interview sample. As both surveys went on, it became clear that they measured different things and that both approaches were needed.

The decision to take the examination survey to the people opened up a nightmare of logistical complications: it meant establishing good relationships in 42 sample locations with medical and dental societies and public officials whose support was needed to get the persons selected for the sample to come in for examination; locating sites for the trailers which formed the examination center and for a field office; living arrangements for a staff who would stay in an area only a few weeks; contracts and permits for utility connections; laundry; cab service to transport examinees to and from examination; stocking an endless list of supplies required for the clinical examinations. Getting it all together and then transporting the equipment, supplies, and personnel from area to area represented an infinite number of possibilities for things to go wrong.

The idea was so new and the problems seemed so difficult that contingency plans were made. The population sample was designed in subsets. If the survey had to be stopped after one subset, at least a representative sample of the population would have been covered.

In field reports from that time, the United States seems to consist of a series of flooded roads, inept plumbers, and a generation of older Americans who seemingly had never been to a physician and did not intend to start with the survey.

Generally, though, the survey teams' reception was good. In rural areas, particularly, the arrival of the trailers that formed the examination center and the field staff was an event to be noted and observed. From rural Wisconsin, where a site near a small-town city hall had been selected for the examination center, the field staff reported: "A prolonged rainy period prior to our arrival had made the location rather swampy so that a bulldozer was required to push the trailers into position; a veritable hurricane on the day of breakdown made this service necessary again to remove the trailers. On both occasions the whole town from the mayor to the village idiot was on hand to enjoy the show and offer advice. All officials were cooperative, however, and did much to make our stay both pleasant and successful."

In rural Alabama, the team reported, ". . . whether in church, stores, or restaurants, groups would approach our personnel with inquiries relating to the survey. The genuine interest expressed by these persons indicated that they thought we were performing a real public service."

In urban and rural locations, headquarters and field staff together generated enough support and publicity to inform people of the survey's presence and purpose. Only a few newspaper stories carried such headlines as "Public Health Service Seeking 150 People to be Research Guinea Pigs." Survey representatives visited, and revisited, prospective examinees to persuade them to accept the examination, and rescheduled broken appointments and then rescheduled them again.

And it worked: between October 1959, when the first cycle of the Health Examination Survey opened in Philadelphia, and December 1962, when it closed in South Carolina, the field staff traveled to 42 sampling locations in 29 States. They examined 6,672 persons, 85 percent of the sample—a remarkable achievement. The survey was conducted with the same concern for the quality of the findings—from performance of replicate examinations of a portion of the sample to the design of a special harness for fastening down the electrocardiograph in the trailers during transit—that had been demonstrated in development of the interview survey.

Moving On

A description of the National Health Survey program published in 1958 pointed the way to the future. It said that "other types of studies are also a part of the Special Surveys program. For example, the universe of hospitalized illness and injury may be studied from a sampling of hospitalized discharges . . . medically attended illness may be surveyed by appropriate samplings of doctors and their practices. Such surveys require extensive methodological study, however, before they can be put into effective operation."

By 1960, when the National Health Survey and the National Vital Statistics Division were combined to form the National Center for Health Statistics, the National Health Survey had begun to move ahead in the development of surveys based on records of health facilities and providers. Work began with the basic step of developing a roster of all facilities for inpatient care in the United States. This Master Facility Inventory, as it was called, was used as a basis for sampling and as a source of statistics on resources.

By 1960, a philosophy of data collection and dissemination had been developed and proved to be both workable and worthwhile. The National Health Survey in 1981 encompasses many more data systems, as the accompanying list indicates, but the traditions set 25 years ago are still strong.

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