

Building Robust Statistical Systems for Health

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By Daniel Melnick, Ph.D.

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*Dan Melnick Research Inc.
6005 Loganwood Drive
North Bethesda, Maryland 20852
danmelnick@att.net*

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Introduction¹

Robust systems to report health statistics promote public health. This paper explores how such systems have been, and can continue to be, built. It draws on the historical record as well as interviews with users and creators of health statistics². As such, it is a study of the institutions and constituencies that support health statistics. Institutions are the manifestation of shared expectations about behavior, in this case, what information is recorded, compiled, analyzed and presented.

This paper illustrates some of these issues and suggests common themes that might be helpful for future planning. It also shows how the challenges increase as the demand for information grows in volume and diversity while institutional resources remain stable. It is easier to increase funding in a short period of time, than to build the capacity to collect and appropriately use data quickly.

Physicians and other medical workers trained in different disciplines look for distinct indicators of disease and wellness. They focus on data that is drawn from clinical experiences and reflect their separate professional and public perspectives. As a result, they look for different health statistics and have diverse standards of excellence.

To meet these demands, health statisticians must draw from diverse materials that span varied records, tests, and surveys. They compile this material from clinical records, surveys and a variety of administrative records including many that are not collected in medical settings. For example, sources may encompass birth and death certificates, health surveys, hospital and physician's

¹ The research reported in this paper was supported by the U.S. Department of Health and Human Services.

² I was particularly helped by the advice and counsel offered by members of the National Committee on Vital and Health Statistics. As well, I want to thank the staff of the Library of Congress, the National Library of Medicine and the Library of the United States Bureau of the Census who helped me to find useful material. This paper is based on interviews with a large number of knowledgeable experts including staff of the National Center for Health Statistics, Agency for Healthcare Research and Quality, several the National Institutes of Health, the Congressional Research Service of the Library of Congress, the General Accounting Office, Congressional Committee Staff and local officials. During a trip to Madison, I held discussions with the staff of the State of Wisconsin Division of Health Care Financing and Public Health. Insights gained from these interviews are reflected in this paper. However, by agreement, the paper does not attribute views or directly quote those who agreed to speak frankly with me.

office charts, records of workplace accidents, toxicological tests, and highway crash accounts. In many instances, health statisticians develop networks to facilitate collecting and compiling information. To succeed health statisticians collect new data and also use existing information. Any particular part of the effort will critically depend on the match between the purposes for which statistics are produced, the methods of compiling the information and the relevance of the resulting presentation.

Beyond collecting data, a key skill is translation: the ability to traverse alternative perspectives and provide information that will be useful for diverse purposes. Therefore the key resources are the facility to inspire and require compliance with data collection protocols and the knowledge of analysts who must bridge the needs and goals of respondents, compilers and information consumers.

To do this job effectively, health statisticians must maintain high standards of professional integrity: that is to say, they must be seen as and, in fact, respond to the *questions* policy makers and the public ask, but not necessarily provide the *answers* leaders would prefer to have. Robust health statistics systems carefully guard this independence from policy direction. Even if it was not ethically imperative, the differing pace of change in policies and statistical systems soon weeds out systems that do not retain their autonomy.

Political forces produce a new cast of decision makers from year to year. Each new set may focus on different problems and demand new kinds of information. In contrast, health statisticians need scores of years to construct and refine data collection and reporting procedures. First, they must define the conditions and services that are measured. Second, they must design procedures to reliably collect and compile data. Third, they must convince diverse respondents to allow them to collect this information. Fourth, they must test the validity and reliability of their procedures to identify their characteristics and limits. Fifth, they must compile data for sufficient time to show changes. Finally, they must present a clear analysis of the trends and variation between important groups in the population. [To be effective, even seemingly simple tables must be based on a cogent analysis.] By the time this work is completed, most of the policy makers who asked for it have moved on to other interests.

In other words, to be effective, health statistics agencies must persist from one policy regime to another. Given the lag between identifying needs for health statistics and building capacity to respond, only systems that can respond to varying policy perspectives while retaining credibility can last long enough to provide meaningful information.

Policy proponents use health indicators to argue for their positions. They understand that statistical data can be turned to many uses. However, legislators look to statistical agencies to provide unbiased accounts of trends. They want to measure each advocate's contentions against unadorned factual presentations.

[Advocates include representatives of interested organizations, the public and also legislators themselves.] Lawmakers seek out independent statisticians who are not tied to particular policy perspectives and do not emphasize conclusions that fit a policy agenda. They understand that the debates are enhanced by unbiased views. Proponents may fashion arguments interpreting the results to reflect their own preferences and values, but at least unbiased statistics provide a factual basis for the discussion.

In contrast, many public health workers look for statistical series that help them to promote healthy public actions. As such, they weigh each indicator against its contribution to better health practices. In other words, they use health statistics to advocate for positive health behaviors and appropriate public policies. Health statisticians are challenged to generate support from this key constituency while at the same time maintaining their independence from any particular health campaign.

Focus on Users

Health statisticians produce as well as use data. Robust health statistics institutions respond to the need for information. To understand its importance we must examine how people use these indicators.

Consider the difference between a statistical record and a medical chart. Health statisticians track the antecedents, incidence and prevalence of disease and wellness in the population. As well, reporting on individual disease events also plays an essential part in health statistics. The reports of individual disease events can then be viewed over time. They report on the use and availability of health care for groups of people. They examine the impact of health status and health care on a nation's society and economy.

In contrast, individual health records are designed to monitor the progress of particular medical incidents. These records, when abstracted, become health statistics. For example, cancer incidence, hospital discharge, and communicable disease data are based on medical records. Health statisticians focus on noting the facts that could affect the quality of care and outcome of that particular case. Medical charts focus on the particular facts that the note-taker believes are relevant to a particular incident involving an individual client or patient.

Health statisticians compile information from these records for statistical analysis. They aim to provide standard indicators that can be reliably combined into aggregate estimates. Health statistics is designed to provide population based indicators. Researchers use these indicators as a basis of comparison for their studies. Practitioners look to them for standards against which they can judge particular measurements of individual patients. For example, whether their height and weight falls into a typical range. The public and policy makers refer to them to help measure progress or decline of health in their community or nation.

The perspectives provided by health statistics are critically important for several reasons:

- First, many of the improvements in health that have occurred during this century resulted from societal efforts to build the infrastructure for health. In fact, better information is a key part of the infrastructure because it helps to identify problems and solutions and to craft both prevention efforts as well as responses to disease.
- Second, health conditions and our responses to them are critical parts of the overall quality of life. Health statistics fill out important parts of our understanding of human progress. Health trends interact with the economy and society. Considering only health care expenditures, the Office of the Actuary of the Health Care Financing Administration [HCFA] estimates that these grew from 5.1% of GDP in 1960 to 13.5% of GDP in 1997.
- Third, in planning resources to prevent disease and care for its victims, both public and private providers, decision makers and consumers need information about the occurrence of health conditions as well as the extent to which current and past needs have been met. Without this information, private providers and insurers are hard pressed to plan their resources to meet demands. As well, public institutions—such as the Congress, state legislatures, the executive branch of the federal government and local health authorities—find it difficult to estimate the cost and impact of existing programs and new proposals. This information is needed whether or not publicly supported resources are provided³.
- Fourth, health statistics provide key indicators of the quality of life in a nation and the capacity of people to meet their expectations. While economists measure satisfaction in monetary units, the overall health of a population provides an alternative view. In fact, disparities in health status, availability of care and resulting rates of disability are an important factor in achieving life long goals. As such, health statistics are central indicators of societal health.

Thus, the key distinguishing feature of health statistics is that they are focused on describing population health conditions, the care provided to people and the effects of wellness, disease and care on the nation. The records serving as

³ For an example of a recent report using Health Statistics data in this way see, United States. General Accounting Office. *Adults with Severe Disabilities. Federal and State Approaches for Personal Care and Other Services.* May 1999. [GAO/HEHS-99-101]

the sources for these analyses are frequently collected for multiple purposes—as such they provide documentary substantiation of important events [births, deaths, hospital bills, care provided] and are also sources for public health and healthcare indicators. Health statisticians transform these records into information that physicians, administrators, public policy decision makers and the public use to understand health conditions, and respond to them.

Because a large part of the improvement in health status and care during 20th century can be attributed to societal changes in factors that promote health, analysts derive related statistics from a broad body of experience. As well, concerns about providing care to the population lead to the need for information about accessibility of medical services—their distribution to different income and social groups. Designing and implementing health interventions requires societal information about conditions, care and the distribution of each. Health statisticians design their procedures to meet these needs.

Health Statistics Form an Infrastructure for Public Health

Unlike a targeted study, where success is measured by its particular contribution to understanding a specific problem, health statistics must provide the infrastructure for a wide body of studies as well as for planning and implementing responses and tracking health effects. As a result, health statisticians find themselves pulled in various directions. Success lies in developing the skill of anticipating requirements and the foresight to prepare for them. At the same time, decisions about the conditions to track and the reports to issue can help to define policies and in turn shape the need for more data.

Persuading diverse professional and service networks to provide data poses a special challenge. To be sure, legal requirements authorize public health authorities to compel compliance. However, they lack the resources to impose their will absent a consensus that reporting is beneficial and appropriate. Anticipating emerging requirements and actually providing for them are distinct tasks. Doing this in a timely fashion is an added challenge. At the same time, organizations that analyze and present information on health trends must balance the need to provide policy relevant information [in the short run] with the requirement that they maintain series showing developments overtime.

To collect valid information, health statisticians must develop specialized methods and convince health care professionals to provide the needed information. These efforts take time: first, to convince those who must authorize it to provide a mandate and large amounts of money. Then to figure out how to work effectively, actually begin compiling the information, process and report it.

Additionally, a key factor in implementing this mobilization is the need to convince health workers and their institutions to cooperate. Faced with limited resources, medical staffs are accustomed to triage. When asked to provide information or access to records they ask: what contribution will this activity

make to improve public health? Or more pointedly, how will it help us to provide better care to our patients? Health statistics agencies need to show how objectively presented data will promote health by facilitating appropriate decisions. Because medical providers offer service to a geographically defined population—i.e. the people living in the communities they serve—rather than the whole nation, they sometimes find it difficult to see the connection between national or even state data and the job they do. Locally targeted data might be preferred to higher quality national indicators, because providers feel that they can discount the imperfections in local data but do not know how to apply the national trends to their specific situation. In fact, much national and state data can be disaggregated in to local data.

While health statisticians are busy developing and arraying their forces, consumers demand almost immediate results to help them meet their pressing needs. Data users see disease and poor health critically degrading the lives of those in their care—or in the case of the public of themselves. They want the most current and best estimates of the distribution of these problems and the factors that create or can mitigate them. Being told to wait for decades while an infrastructure is fielded is simply not acceptable to them.

In this sense, the tension placed by the demand for health statistics is not unlike the dilemma faced by basic medical research. There too, the lag between design implementation and results can be decades long. However, consumers judge the impact of statistical work by its ability to provide current information rather than its contribution to fundamental—and by definition long lasting—knowledge.

Health statisticians can only respond by using the data forces already in the field. This means that there is an inevitable lag between the identification of needs and the delivery of appropriate data. During this lag, [as we will see below] health statisticians must still provide the best possible answers. They do this with varying degrees of success.

National Health Statistics and the Organization of Medical Fields

Consider the differences in perspectives between statisticians, researchers and practitioners. Health statistics are important in developing, targeting, and evaluating public health policies and programs, at local, state and national levels. Health statisticians report on the condition of populations. Medical researchers and caregivers often focus on particular diseases. Each medical field addresses the antecedents, conditions and consequences of particular types of illnesses. And each one has articulated distinct expectations about the need for and ability to obtain incidence, prevalence and population data, as well as, the appropriate techniques required and the particular public concerns that must be overcome. [Incidence refers to the inception of new cases, while prevalence to the number or proportion of people afflicted. Thus, both measure the impact of disease or

wellness on a defined population.] This in turn leads medical researchers, practitioner, providers and insurers to rely on a variety of procedures to obtain population based data.

These perspectives grow out of the particular experiences of researchers and care givers. They reflect the development of different medical disciplines that result from and are at the same time, the inception of distinct methods of research and surveillance.

The Incidence of Cancer and Heart Disease

For example, consider the distinct approach to measuring incidence and prevalence of cancer and heart disease. To be sure, the diagnosis of cancer relies on specific pathology tests. Heart disease is more difficult to identify. And yet, the acceptance of cancer incidence measures and the general lack of such measures for heart disease stems as much from decisions about the infrastructure of research as it does from the particular doctrines of the medical disciplines. In the decades since the declaration of war on cancer, the National Cancer Institute built a system for monitoring cancer incidence, prevalence and survival. This system [SEER] uses cancer registries located in selected areas [and administered in cooperation with locally based practitioners] to collect information on time of diagnosis and survival. These are combined with national statistics from the NCHS Vital Statistics Program to report on incidence, prevalence, and survival. Two underlying assumptions are key to this system of national cancer statistics:

- That cancer incidence is coincident with the first diagnosis of pathology—measured by a definite diagnosis of cancer. And
- That the experience in the selected registry areas is indicative of national trends.

These assumptions are supportable because cancer experts are willing to agree to accept registry area information as nationally indicative and to equate incidence with a definitive finding of pathology. An important consequence of these assumptions is that users need to exercise particular attention when interpreting cancer statistics. For example, as diagnostic procedures improve, cancer incidence could increase. Experts generally recognize this as an artifact of improved procedures rather than a real increase⁴. Likewise, if a particular type of cancer is related to a local condition—such as an environmental hazard or concentrated behavioral pattern, the assumption that national incidence rates can be inferred from selected areas might be wrong. Likewise, national estimates may not be indicative of local conditions.

⁴ These issues are not limited to the measurement of cancer incidence. For example, when tests for the HIV virus were developed in the 1990's these changed the diagnostic definition of AIDS and shaped the measurement of its incidence.

The cancer field agreed to live with these imperfections in view of a larger need to collect and report medically confirmed cases of cancer for particular cancer sites. As they see it, cancer is not one disease but a group of afflictions. Thus, tracking incidence, prevalence and survival of different cancers is more important than probability based national estimates or incidence estimates derived without reference to pathology tests. Consequently, the field determined that knowing about variation between types of cancer was more important than a precise measurement of incidence. They contend that the variation between registry and non-registry areas was less important than the variation between cancer sites.

The SEER system of course, suffers from limits that distinguish it from national health surveys. Its registry data only covers a limited number of states. It collects extensive data which may not be an efficient procedure for collecting population based indicators. Generalizations from its results require the assumption that the same patterns observed in the SEER registry areas extend to the balance of the country. Efforts under way at CDC and NCI may result in an increase in the parts of the Nation that are included in cancer registries. As well, the coverage of these areas may improve. Nevertheless, thirty years of data showing the most complete series related to cancer are based on the SEER registry areas.

The appropriateness of these decisions is not at issue here. Rather, what is important is to recognize that they involve professional judgment about the kinds of statistical systems to construct and the kinds of measurements to accept. We might say that the statistical infrastructure is a reflection of professional constructs that shape how variables are analyzed and presented.

In contrast, consider how researchers and physicians dealing with cardiovascular disease or CVD handle the measurement of incidence [or perhaps it is better to say, the difficulty in measuring incidence.] This field bases its decisions regarding the measurement of incidence on the identification of factors that lead to CVD. These factors often exist without signs or symptoms of disease. For example, a person might manifest the initial stages of CVD without being diagnosed. As well, diagnosis is more difficult because there is no generally accepted threshold analogous to the pathology reports used to classify tumors as benign or malignant.

Of course, cancers frequently are also not diagnosed in their early stages. Pre-cancerous conditions might lead to cancer. The difference between the two fields arises as much from different diagnostic conventions as it does from differences between the diseases. In the case of heart disease, it has also led to greater reliance on cause of death statistics [based on the National Vital Statistics System] as indicators of the prevalence of disease. Sample surveys such as the National Health Interview Survey, and to a greater degree, the National Health and Nutrition Examination Survey also provide the available information. Research workers in the field rely more on longitudinal studies of particular

communities—such as the Framingham study—because these studies focus on the development of disease that provides the major questions for research.

From the perspective of users who need to compare the impact of cancer and heart disease on populations, this means that with the exception of mortality statistics, they must use different measures. This makes it difficult to compare the relative effect of these major diseases on populations.

Thus, differing expectations between researchers and physicians working on cancer and heart disease critically affect their use of, and confidence in, different types of health statistics. Some of these differences can be attributed to the magnitude of prevalence—clearly where problems affect large proportions of the population, probability samples of the household population can more easily find and report on them. In other cases, successful fielding of data collection is impacted by the articulated views of constituencies formed by those affected by or concerned with particular diseases [such as HIV/AIDS, Cystic fibrosis, or Breast Cancer.] These constituencies are frequently effective in focusing resources on the collection and reporting of information about the diseases that afflict them.

As a consequence, disease based medicine relies on separately established networks to obtain and report data. These networks set the standard for

- Record keeping,
- Classification of conditions [for example, defining when it starts],
- Populations measured [for example, through registries or probability samples],
- Acceptable measurement procedures [for example, whether patient reports are sufficient or diagnoses are required] and
- Authoritative reporting methods [for example, whether statistical series are featured or peer reviewed literature is required.]

Health statisticians must contend with these viewpoints and find a way to reconcile them with their mandate to provide information on health conditions that affect the general population.

Striking the Right Balance

Health statisticians face the difficult task of balancing the need for information that:

- Describes the distribution of health antecedents, conditions, care and consequences on the population, society and economy

- Provides estimates of the number and distribution of people in need of and receiving medical or prevention interventions
- Provides population controls for medical investigators and
- Alerts public health authorities as well as those who plan and provide facilities of emerging needs for care.

Each of these purposes demands a different kind of data collection, using distinct sampling plans, and responding to different standards of accuracy and relevance. In fact, none of these health statistics systems exists to meet a single purpose. To meet these needs, health statisticians must draw on diverse data sources including:

- Administrative records of care--such as the hospital records that are abstracted for the Hospital Discharge Survey
- Reports of specially identified 'Notifiable' conditions --such as those tracked by the Epidemiology Program Office of CDC or those included in the NCI's SEER cancer registries
- Specially designed community surveys or observations -- such as those conducted by some of the grantees of the NIH institutes⁵ and
- Nationally representative studies [or at least studies that are representative of a defined population.] -- such as the National Health Interview Survey, NHANES, the National Immunization Survey, and the National Survey on Family Growth.

Health statisticians make a distinct contribution. They relate the findings from these studies to generalizations that inform personal, organizational and public decisions⁶. To do this effectively, health statistics systems must anticipate the needs of policy makers and provide timely, valid and reliable information.

Resources

The principal resource health statisticians bring to the field is access to the myriad networks that supply, condense, and use health data. In almost every

⁵ NIH Institutes have also recognized the need to support surveys based on national probability samples.

⁶ An excellent example of the utility of this type of analysis can be found in the recent work of the GAO's Health Service Quality and Public Health Issues section. For example see. General Accounting Office. **Lead Poisoning: Federal Health Care Programs Are Not Effectively Reaching At-Risk Children** [GAO/HEHS-99-18] January 1999. This study drew information from the NHANES, the Medicaid Billing Data compiled by HCFA, SIPP and the CPS.

interview I conducted respondents identified an individual or a set of individuals whose special expertise provided this access. This included policy makers who turn to specific experts for help in understanding and navigating health statistics, medical researchers who rely on specialized staff to obtain the appropriate results, and health statisticians who turn to data experts for help in fathoming the meaning of the results they obtain. If success is defined as the ability to extract information from uncertain data, then these experts are the key to success. Supporting their efforts is a fundamental requirement of building a health statistics infrastructure. At the same time, these data experts turn to policy analysts for help in identifying emerging needs.

Approached in this way, we can see that the infrastructure of health statistics is best viewed as a network of complementary and cooperative relationships built on mutual respect for different professional standards and practical requirements. Each medical specialty develops its own norms that respond to the particular problems it faces. To be sure, physicians are only one supplier of health statistics. Health statisticians must work within those norms and at the same time fashion consistent population based indicators.

What follows explores the factors that lead to success in this enterprise. It considers several historical examples and the insights provided during interviews with users and creators of health statistics. Next, we look back at the history of health statistics to understand how policy makers and the public were affected by gaps in information that characterized the field during the first half of this century.

Historical Perspective

Reporting health statistics that represent conditions in the whole nation is a very recent innovation. In the United States, the practice of collecting and reporting regular series showing Nationally representative health conditions developed during the last 75 years. Before then, the information we had was largely derived from partial studies focused on communities or from birth and death data reported or inferred from the decennial census.

Birth and death data have been collected in America since 1639, and at the state level since 1841. Communicable disease reporting at state levels started during the 1870s. However, a national system of death and birth reporting although started in the early 1900s was not completed until 1950.

For example, during the first half of the 20th century, insurance companies developed statistical programs to report on the health experience of their clients. They needed this data to estimate premium costs. Speaking in 1914 before the annual meeting of the National Organization for Public Health Nursing, Frederick L. Hoffman, [the statistician for the Prudential Insurance Company of America] urged public health nurses to adopt uniform reporting forms so that the information they collected could be analyzed for trends and provide a basis of statistical comparison. Hoffman reported that despite the best efforts of

statisticians working with data on illness, “no trustworthy data are available for a concise statement of the actual situation.”⁷ Hoffman urged the public health nurses to adopt a standard form designed by the statistical staff of the Prudential Insurance Company⁸.

The following examples illustrate the lag of 30 to 50 years between the identification of the need for a particular health statistics infrastructure, its development and full operation. They show how health statisticians must articulate the need, develop procedures, convince their network constituents of the success of these procedures, field forces to implement them and put regular reports in place.

Developing an authoritative system to compile and collect health data is a key element in its success. As a practical matter, using the authority vested in governments to mandate or require the collection and reporting of health statistics mostly accomplished this. To be sure, private organizations [such as the American Medical Association, the Milbank Memorial Fund, the Robert Wood Johnson Foundation and the Metropolitan Life Insurance Company] used their authority in limited areas to collect and report on trends. However, only local, state and federal government agencies have been able to cover the field broadly sustaining integrated sets of health statistics. Private organizations have seen their role as focused on their particular concerns. In fact, an important contribution of the private sector was to pioneer the field demonstrating what needed to be done and spurring the government agencies on to continually expand and improve their work. In the early decades of the century, voluntary societies, foundations and corporations struggled to fill gaps left incomplete by the government system for collecting and reporting health data.

Vital Statistics

A summary of United States health statistics prepared by Halbert Dunn of the Bureau of the Census for the Central Statistical Board in 1940 described the limited data available. Dunn reported that the United States did not “possess a complete national registration system of births and deaths” until 1933. It was

⁷ Frederick L. Hoffman, LLD. “Practical statistics of public health nursing and community sickness experience.” Prudential Insurance Company of America address delivered before the National organization for public health nursing St. Louis April 25 1914. [In the collection of the History of Medicine Division, National Library of Medicine.

⁸ The insurance companies provided the United States Surgeon General with statistical information about the causes of death drawn from the experience of their policyholders.

only in 1936 that the Bureau of the Census was able to publish general life tables for the "entire continental United States for the year 1930."⁹

A "long, hard-fought, and often discouraging campaign of individuals, associations, and State and Federal agencies" established the Vital Statistics system. In more than 50 years of work, federal and state officials established a network of doctors, hospitals, mortuaries, and ultimately families tied together by state and local government agencies and reporting to statisticians working for the Federal government¹⁰. Because of the Federal structure of the United States Government, the recording of vital events developed as a State responsibility. These records were needed to legitimate membership in American society but were not collected with uniform procedures before the turn of the 20th century.

The gap was filled during the 19th century with information collected during the decennial census, but this was widely regarded as unreliable¹¹. For example, in 1869, Hon. James A. Garfield called for the collection of disability statistics as a part of the census of 1870. He strongly criticized the previous practice of counting "deaf, dumb, blind, insane, idiotic, paupers and convicts" on the census schedule. Garfield wanted the census to collect information on those "who have lost a limb or have been otherwise disabled" as a result of the Civil War. He looked to the census to "show the state of public health and the prevalence of some of the principal diseases."¹²

⁹ See Halbert L. Dunn. "Vital Statistics, Health, and Medical Care." In Elizabeth Phelps, Ed. *Statistical Activities of the American Nations 1940*. InterAmerican Statistical Institute. Washington D.C. 1941. The United States material in this book was prepared under the direction of Stuart A. Rice of the Central Statistical Board.

¹⁰ See Alice M. Hetzel. *U.S. Vital Statistics System Major Activities and Developments 1950-95* National Center for Health Statistics. Centers for Disease Control and Prevention, US Department of Health and Human Services. 1997. [PHS 97-1003] This report also contain a reprint of *History and Organization of Vital Statistics System* which first appeared in 1950 and traces the development of vital statistics from the beginning of the republic to 1950.

¹¹ DeBow noted that "The tables of the census which undertake to give the total number of Births, Marriages, and Deaths, in the year preceding the first of June, 1850 can be said to have but very little value. Nothing short of a registration system in the States can give the required data satisfactorily, and it has been proved that even where such systems have been best established, difficulties continually arise which require a very long time to be removed." As quoted in Vital Statistics of the United States, Vol 1, 1950 reprinted in *Hetzel* p.48

¹² James A. Garfield. *The American Census*. [A paper read before the American Social Science Association, at New York, October 27, 1869. New York, Nation Press 1869. As reprinted in Congressional Research Service. Library of Congress. *The Decennial Census: An Analysis and Review*. Prepared for the Subcommittee on Energy, Nuclear Proliferation and Federal Services of the Committee on Governmental Affairs, United States Senate. Committee Print. November 1980. pp.273-274. Garfield was chairman of the Congressional Committee on the Census at the time.

After the 1910 census, the Congress established the Census Bureau as a permanent organization and confirmed its mandate to compile vital statistics from the states. The Bureau began working to encourage the spread of birth and death reporting. The Bureau spent several decades working to extend the birth and death registration areas and only succeeded in completing this system in 1933 when Texas was finally covered¹³.

The need for vital statistics was well understood by the turn of the 20th century. In 1915, John Trask, the Assistant Surgeon General articulated its importance for the improvement of public health. Trask reports on the development of uniform model laws for adoption by state governments. These laws provided for the collection and reporting of birth, death and morbidity data. The adoption of these laws was only the first step in effectively collecting this data. Trask noted that in the United States:

Physicians and midwives have in many instances not yet come to realize that the importance of proper registration may mean so much to the child and its parents that no accoucheur has completed his task nor fulfilled his obligations to the child and its mother until an accurately filled out certificate has been filed with the registrar. The failure to file such a certificate is such a neglect of the interest of both patients, the child and the mother, that it would seem proper to class it as malpractice¹⁴.

Trask identified major sources of error in birth, death and morbidity statistics. He writes that the major source of error in birth statistics comes from the failure to report, while mortality statistics suffer most from the inaccurate or incomplete recording of the cause of death. Trask described early attempts to achieve uniform registration laws that would address these issues. He reports that a model bill was drafted and endorsed by the American Medical Association in consultation with the Census Bureau and the Children's Bureau as well as the American Public Health Association, the American Bar Association and a number of other organizations.

The depression brought major changes in the demand for this information. In particular, vital records "suddenly became important to large numbers of individuals, who for the first time in their lives had to prove vital facts about themselves."¹⁵ In particular, these records played an important role in enforcing

¹³ Hetzel p. 54

¹⁴ John W. Trask Vital Statistics: A Discussion of What They Are and their Uses in Public Health Administration. Supplement No. 12 to the Public Health Reports April 3, 1914. [Third Edition] p. 22. United States Public Health Service. Government Printing Office. Washington 1915.

¹⁵ Hetzel p. 55

labor laws, welfare programs and the new Social Security program. Pension plans increasingly used them to establish age. During the Second World War, laws prohibiting the employment of aliens in certain defense projects placed a greater emphasis on the birth certificate as a proof of citizenship. The Census Bureau estimated in 1940 that as many as 55 million native born persons did not have a birth record¹⁶.

Studying these issues in 1943, the Bureau of the Budget recommended moving the vital statistics office to the Public Health Service and establishing the current cooperative vital statistics system to preserve state responsibility while increasing coordination. This move was accomplished in the President's Reorganization Plan No. 2 which transferred authority for vital statistics to the Federal Security Administration [FSA]. In 1960, the FSA's vital statistics functions were incorporated into the newly formed National Center for Health Statistics.

The vital statistics registration system was not fully in place until the 1950s¹⁷ at which point it grew to provide increasingly detailed and standardized information about the circumstances of birth and the cause of death. The standard birth and death certificates collected increasingly more detailed information about the circumstances of births and the causes of death¹⁸. Birth and death records were linked for special studies. NCHS worked with the Census bureau to survey relatives and health care providers of the diseased and compile more detailed mortality data for nationally representative samples.

Reviewing the development of vital statistics, we can see that health statisticians play the role of extracting uniform and reliable data from administrative records. They take advantage of the opportunity offered by the need to legitimate and record membership in American society at birth and at the time of death. Over time, they have been able to collect an increasingly valuable set of health related information and relate it to other sources. These benefits rely on the cooperation of physicians, hospitals, parents, relatives and mortuaries. In other words, the legitimacy of recording vital events to establish societal membership provides the occasion to obtain compliance in collecting health information. But this strategy can only succeed because there is general

¹⁶ *IBID* p. 55 on this point, it should be noted that Trask also wrote in 1914 that identification of the child was a principal purpose of the birth records. See p 21 of his report.

¹⁷ For example, Jacob Siegel noted that the birth registration of African Americans was incomplete in several states until 1950. See United States. Bureau of the Census. *Developmental estimates of the coverage of the population of states in the 1970 census : demographic analysis* by Jacob S. Siegel ... [et al.] with the assistance of Donald S. Akers, Mark D. Herrenbruck. Washington: U.S. Dept. of Commerce, Bureau of the Census, U.S. Govt. Print. Off., 1977.. Current population reports : Special studies : Series P-23 ; no. 65.

¹⁸ See *Hetzel* pp. 28-42 for a complete list of the variables included from 1900 to 1995.

agreement on the importance of collecting the health information and on a common set of data items. This consensus was built during more than 50 years of slow and careful propagation.

Health Surveys

Trask's 1914 report identified three types of vital statistics data--birth, death and morbidity. However, while the birth and death records grew more uniform and plentiful over the next 35 years, morbidity data became less useful. Trask envisioned a morbidity reporting system with a long list of notifiable illnesses. These however, were predicated on the idea that the most important diseases were communicable. This gave physicians a direct stake in reporting although Trask noted:

Among practicing physicians, at least in the United States, there has at times been the feeling that the knowledge of a disease in patient is privileged information which they should not be called upon to impart. In communities where the laws require the notification of the disease this feeling has no legal basis and the physician who does not make report is not a law-abiding citizen. Every physician has a number of individuals or families who look to him, and properly so, not only for treatment, but also for such reasonable protection from disease as he is able to give. The failure to report the occurrence of a case of communicable disease in one patient may lead to its spread to others among his clientele whose rights he has ignored. He therefore violates the intent and spirit of the ethical principle of the protection of patients among whom must be considered the well together with the sick... the physician who fails to report his cases of preventable diseases... [is] actively obstructing public health administration.¹⁹

In pre-World War I America, communicable diseases were the major threat to health. However, in subsequent decades communicable diseases were matched by other sources of morbidity. Policy makers, providers and insurers who wanted to respond to the public's need for health services looked to health statisticians for information about the prevalence and incidence of cancer, heart disease, diabetes and other non communicable conditions. The first important crisis followed the onset of the economic depression in 1929. Whatever the success of obtaining information about communicable diseases through surveillance based on a list of notifiable diseases, this method was not well suited to get a complete picture of all of the sources of morbidity.

¹⁹ **Trask** p.44 The current disputes concerning sharing electronic medical records echo the concerns Trask addressed in this passage.

There were several attempts to study discrete communities to obtain information about morbidity and the etiology of diseases. [In fact, this approach is still supported by the NIH.²⁰] These studies help to obtain detailed longitudinal or panel data that can trace the factors that are associated with illness. But they are not generally regarded as suitable for providing information about the distribution of conditions in the general population or for estimating the number of persons at risk. A key problem is that they are limited to the narrow populations that they study. Analysts using them for population estimates must assume that the study group is representative of the general population which requires the further assumption that there is little important variation between the general population and the particular community studied.

The National Health Survey of 1935-36

Using WPA money and workers during the winter of 1935-36, the Public Health Service's Division of Public Health Methods conducted the first National Health Survey of the general population. It was also the largest²¹ health survey conducted at the time with more than 750,000 households in 84 cities and several rural areas. The survey results that were widely reported and relied upon were the source of considerable controversy.

While conforming to the methodological standards of the early 1930's, the procedures used in the survey were soon overtaken by the development of improved survey methodology in other fields. For example, this survey did not use a probability sample, or an interview schedule and was largely confined to urban areas. [Enumerators were given a set of instructions and asked to complete a form but were not given the exact wording of the questions or the order in which they should be asked.] Policy makers relied on the data collected in the winter of 1935-36 for statistics about health conditions until the "continuous" national health survey [now called the National Health Interview Survey] reported its first results after 1957. Until then, analysts working at the Public Health Service updated the 1935-36 estimated **counts** by combining them with population information obtained from more recent census data, but they did not have a way of updating the **rates** of morbidity during a period of substantial change in American health conditions.

Following best practice of the early 1930's, the "enumerators" recruited a household informant who was asked about the health of her [most of them were

²⁰ For the most famous example of this see, Thomas Royle Dawber *The Framingham study : the epidemiology of atherosclerotic disease*. Cambridge : Harvard Univ. Press, 1980.

²¹ It may well be the largest health survey ever conducted. The National Immunization Survey has a larger number of screening interviews but fewer actual full interviews. The 1935-36 survey collected information on all members of the household giving it a person sample of more than 2.5 million people.

housewives] family during the previous 12 months. Enumerators completed a form based on instructions providing general guidelines regarding how to identify periods of disability and the illnesses associated with those periods²². However, they did not use a defined schedule of questions. Respondents were asked to recall episodes of illness over the previous 12 months.

Thus, there was a lag of almost 30 years between the early attempts at obtaining population data on morbidity through community studies and the start of the National Health Interview Survey that used well-developed and regular procedures to collect an established data series.

George St. John Perrott [the PHS official who directed the 1935-36 National Health Survey] has left an extensive account of the origin of the 1935-36 survey²³. He describes early efforts in 1929-32 to collect information on the impact of the depression on health status. These efforts were restricted to limited community studies that were used to project estimates of the number of persons affected by acute and chronic illnesses and the effects of disability²⁴. Perrott describes how Harry Hopkins decided to correct this deficit by transferring \$3.5 million in WPA funds to the Public Health Service to support the survey. Perrott's staff recruited interviewers who visited more than 750,000 households in 84 cities and several rural areas.

Clark Tibbitts an employee of the Bureau of the Census was transferred to the Public Health Service to direct the fieldwork. Tibbitts used the most up to date 1930's Census methods to conduct the survey. This project preceded the

²² For a description of the procedures used see, George St. John Perrott, Clark Tibbitts and Rollo Britten. *The National Health Survey. Scope and Method of the Nation-wide Canvas of Sickness in Relation to its Social and Economic Setting*. Public Health Reports. Vol 54 No 37 September 15, 1939. Pp. 1663-1687.

²³ Perrott was a physicist by training who was engaged in statistical work during the First World War. He was employed in mine safety studies during the 1920's and was hired by the Milbank Memorial Fund after the crash of 1929 to work on a large study of the effect of the depression on health. When Roosevelt won the election in 1932, the Milbank Fund contributed the services of several staff members to the Public Health Service. Perrott was brought into the government to help PHS make use of the Milbank community surveys -- which were one of the few sources of data about the effect of the depression on health. Working in the PHS--which was at that time located in the Treasury Department--Perrott wrote an analysis of state compliance with emergency rules requiring that people on Home Relief should receive health services. This study tried to estimate the percent of people receiving the services they needed based on State agency reports of the services they offered. Perrott was frustrated by the lack of good morbidity data upon which to base estimates of the number of people in need of health services. He proposed the National Health Survey without the expectation of getting the resources to conduct it. As he described it in his oral history interview, once the funds were transferred, he was ordered to begin collecting data almost immediately and had to scrounge for ways to implement the survey.

²⁴ George St. John Perrott, *Oral History Interview* September, 1966 pp. 20-40 [History of Medicine Division of the National Library of Medicine.]

development of national household probability sampling. The first Bureau of the Census sample survey was conducted in 1937.

Shortly after the results appeared, the American Medical Association severely criticized the procedures used to conduct this survey. They questioned the representativeness of the sample, the procedures used to identify chronic and acute illnesses and the qualifications of the interviewers²⁵. The AMA questioned

*First, the ability of the enumerator or person reporting to determine whether an illness, a chronic disease, or a gross physical impairment was present on the day of the canvass; and second, the ability of the person interviewed to report accurately the illness which had disabled any member of the family continuously for seven days or more during the preceding twelve months*²⁶.

Although the National Health Interview Survey uses more sophisticated methods than were used in 1935-36, some medical researchers continue to raise doubts about the NHIS. Their opinions sound very similar to the objections raised by the AMA in 1939²⁷. In spite of extensive methodological studies conducted to improve the quality of responses, clinical researchers still worry about the self-reported information in the NHIS and question the depth and applicability of the results. These researchers are more supportive of studies such as the National Health and Nutrition Examination Survey, which collect clinical measurements in addition to the reports of respondents about perceptions of their health. [Below we will see that establishing NHANES was a product of a compromise between those who wanted a population based survey, of the distribution of health conditions and care, and their clinically oriented critics.]

These differences should be considered in light of the purposes of such surveys. They provide information about the distribution of health conditions, disability and care among the population. While these factors might be included in a clinical study, clinical studies typically do not derive information that is projectable to a defined population. In other words, they cannot provide a basis for generalizations about the distributions in the population. On the other hand, population based surveys frequently cannot provide clinical measurements.

²⁵ Bureau of Medical Economics, American Medical Association. *A Criticism of the National Health Survey*, July 26, 1939. [typescript . Papers of George St. John Perrott, National Library of Medicine, History of Medicine division.]

²⁶ *IBID* p. 4

²⁷ This statement is based on several interviews I conducted for this paper in which persons responsible for supporting medical research questioned the accuracy of reported conditions in interview surveys including the NHIS.

After the end of the Second World War, it became obvious that the 1935-36 National Health Survey was not adequate to meet the policy makers' need for current information about morbidity. The Public Health Service reported that it was unable to adequately respond to questions about the current prevalence of diseases other than those reported as notifiable. They were accustomed to updating their estimates of the number of people suffering from diseases by adjusting the population figures using the census as a base. PHS proposed a new survey to be conducted using the newly developed probability sampling techniques.

Testifying before the Senate Committee on Labor and Public Welfare in 1951, the Surgeon General of the US recounted the limited nature of the information available to consider health problems of the nation.

A survey of health status of the urban population conducted in 1935-36 was an attempt to find out the number, age, sex, income level, occupation, and location of people in the United States who were suffering from various types of acute and chronic illnesses. It also determined the severity of their disability in terms of time lost from work, days in hospital, days confined to bed, and the like.

In the past fifteen years, findings from the National Health Survey of 1935-36 have formed the basis for about two hundred reports, articles, and comparative studies. The survey data have been used to project estimates for more recent years and for individual communities in an attempt to measure needs for hospital and other facilities and community services.

Many of the National Health Survey figures are of somewhat doubtful applicability to present-day conditions. Rapid developments in medical knowledge, improvements in mass diagnostic techniques, and concentrated efforts to combat chronic illness spell new hope for success in preventing and controlling many types of illness which now sap the vitality and efficiency of thousands of people. Many health and welfare programs need current data on illness and disability.

....

In the past decade and a half, procedures for obtaining representative samples have been greatly improved. Since the National Health Survey, wide experience has been accumulated in the design of questionnaires so that the danger of misinterpretation

*and error on the part of interviewers and persons interviewed may be minimized.*²⁸

However the medical establishment including the AMA and the National Cancer Society opposed this proposal²⁹. They advocated that the money for the survey should be spent to support community studies that could be concluded by qualified health professionals rather than relying on survey interviewers.

After several attempts to get Congressional authorization for this survey, the PHS asked the newly formed National Committee on Vital and Health Statistics to convene a subcommittee to make recommendations regarding the methods for sampling and measurement³⁰.

The subcommittee identified six broad categories of need for morbidity statistics:

- Administrative planning and evaluation
- Evaluation of medical and dental services
- Medical research
- Need for medical manpower
- Planning drug and medical appliance manufacture and
- Public health education³¹.

The NCVHS subcommittee recommended a continuing national survey focused on "the publication of basic data on the prevalence and incident of disease, injuries and impairments " These would be supplemented by special

²⁸ *Testimony of Dr. Leonard Scheele*, Surgeon General of the United States before the Subcommittee on Health, Committee on Labor and Public Welfare, United States Senate, August 23, 1951 unprinted stenographic transcript. Pp. 23 -27. [CIS fiche (82)S Lab-T.1]

²⁹ See their testimony in U.S. Senate. Subcommittee on Health, Committee on Labor and Public Welfare. *Hearing on S. 1328. A bill to Provide for Survey of Sickness in the United States.* August 23, 1951 [unpublished stenographic transcript . CIS fiche (82) S. Lab-T.1]

³⁰ See *Recommendations for the Collection of Data on the Distribution and Effects of Illness, Injuries and Impairments in the United States.* A report of the Subcommittee on National Morbidity Survey. U.S. National Committee on Vital and Health Statistics. U.S. Department of Health, Education and Welfare. Public Health Service. October 1953. The NCVHS was established in January, 1949.

³¹ *IBID* p. 8-9

studies focused on "undiagnosed and non-manifest disease, by means of laboratory screening." They advocated a design that took full advantage of probability sampling.

In the law that passed in 1956, Congress--taking its lead from the NCVHS subcommittee--included a mandate for methods development. This provision led to the development of the National Health and Nutrition Examination Survey that uses medical personnel to conduct clinical examinations of a probability sample of the population of the United States. With the addition of this provision the AMA withdrew its opposition to the survey and the law was enacted.

In 1956 report adopted by the Senator Lister Hill's Senate Committee on Labor and Public Welfare to accompany their recommendation for the new law, they argued that:

"Our most recent comprehensive data are those collected by the National Health Survey in 1935-36. The figures obtained then are still used--with adjustments for later population increases--because there is no later information for the population as a whole. There is a more serious timelag here than appears from the mere passage of 20 years. The last two decades have seen the development of the wonder drugs and the development of many new medical, surgical and rehabilitative techniques. There has been much progress in public-health programs and in the construction of hospitals and other health facilities. We cannot accurately assess what has been accomplished by these advances or estimate with the necessary precision the magnitude of the health and medical problems we still face."³²

Since the survey was first fielded in the late 1950's, it has grown into a continuous vehicle for collecting data on the distribution of morbidity and health status, and care among the general population. Medical researchers and the NIH frequently draw on its results and enhance its content to meet their needs. As well, the NIH participates in supporting several other health surveys--such as the National Survey of Family Growth--that use methods based on those developed for the NHIS. Other agencies within the PHS [for example, AHCPR and SAMHSA] have developed specialized surveys that adapt the procedures used in the NHIS to meet their special needs.

³² United States Congress. Committee on Labor and Public Welfare. *Report No. 1718. 84th Congress 2nd Session*. March 28, 1956. p.2. This report was written to accompany S. 3076 the bill that established the legislative mandate for the conduct of continuing surveys and special studies of "sickness and disability in the United States. This law still provides the legislative authority for the National Health Interview Survey and several other surveys conducted by the Public Health Service. It is likely that the Committee based its findings on a report issued by the National Committee on Vital and Health Statistics in 1953.

The extent of participation and confidence in the results varies with the particular disciplinary perspectives of differing medical fields. As well, the emphasis of resources for data collection critically depends on public interest and public health threats.

Surveillance

In order to respond to emerging trends in disease and promote public health, practitioners recognize the need for information to monitor threats. Using the model of infectious diseases and recognizing the need for concerted societal responses, public health authorities [under the leadership of the Centers for Disease Control and Prevention] have implemented various programs of surveillance. It is important to consider these programs' impact because they use health statistics and at the same time also provide data that can be set in a statistical framework.

A key element of surveillance—as distinct from health statistics—is that surveillance is action oriented by design. Data are collected with the express purpose of alerting health authorities about the need for rapid response to threats—and its success is measured by the efficacy of the steps taken to avert or limit problems. At the same time, surveillance makes use of legal authority to compel reporting and relies heavily on the compliance of practitioners to report 'notifiable' events. This means that it relies on state authorities to implement appropriate regulations and the federal effort relies on local cooperation.

The idea is that certain disease conditions are a threat to persons beyond those afflicted and these conditions should be met with isolation, vaccination and other measures to limit their impact on the population as a whole. Health statistics—such as data from the vital statistics system or survey data—can sometime provide important elements in these threat assessments. However, because surveillance programs are typically targeted to emerging problems, reports of cases filed by physicians and hospitals is an important element of these systems.

An important distinction between surveillance systems and health statistics is the action-oriented design of the former and the indicator perspective of the latter. This explains why surveillance systems are fundamentally different from health statistics. This leads to several important differences between the perspectives of data collectors, reporters and interpreters of these systems.

In particular, surveillance systems are focused on specific circumstances where caregivers believe that there is a present danger to the population or believe that a dangerous situation might arise. As a result, one characteristic of statistics based on surveillance systems is the peaks and valleys typical of reported trends. This occurs because physicians may be more attentive to reporting cases when they believe that there is a pattern of increasing danger—or after such dangers have been noted in the literature. Although the authorities might designate

conditions as reportable, the care with which they are reported varies with the commitment of caregivers to the problem. This in turn is influenced by the perceived sense that important dangers exist. Health surveys while less likely to include such emerging conditions in their scope at first, continue to collect related information regardless of respondents' beliefs about the importance of the information. This means that surveillance systems are more likely to report about a problem earlier, but health surveys form a more stable basis for measuring changes in prevalence and incidence.

Surveillance therefore is rooted in a disease specific approach, while health statistics focuses on whole populations. For example, within CDC's Epidemiological Program Office, there are considerable differences in the attention, resources and reports related to different conditions subject to surveillance. Consider the full and careful series developed to track AIDS compared to other notifiable conditions—such as Hepatitis C. To be sure, this emphasis stems from the particular character of the disease and the need to understand a new threat to the public's health. At the same time, the demand for AIDS surveillance from a well-organized and articulate interest group also effected the allocation of CDCs surveillance resources.

Because surveillance efforts are action oriented their impact on individuals is also more direct. This has the advantage of using results to target efforts towards important problems. At the same time, individuals who might be subject to these efforts may be reluctant to report information. For example, consider the current dispute over the need for surveillance registers to monitor the number of people who are HIV positive. While the compilation of this information would clearly provide early warning of the need for measures to care for future AIDS victims and could also help in controlling the spread of HIV disease, advocates for the rights of HIV positive individuals have raised questions about the effect of these registers on those included in them. While reporting of HIV status is difficult in any case, health surveys may be better able to allay these fears because of their ability to convince participants that information would remain confidential. At the same time, registry data can be based on laboratory tests and physicians' diagnoses while surveys frequently must rely on the respondent's reports of their own condition.

Meeting the Goals

The goals established for the health statistics system as it moved in to the era of modern sampling and measurement techniques called for timely, responsive, and accurate results. To achieve these goals, health statistics systems need to exhibit:

- Responsiveness to health concerns

- Responsiveness to Health Policy Makers
- Timeliness of reports
- Appropriateness of periodicity
- Accuracy reliability and validity
- Accessibility
- Linking results with users requirements
- Appropriate and valid analysis
- Technical accessibility of the results. That is: how the complexity of the design limits who can use the data.
- Cost of the system and the sustainability of support
- Quality of the data
- Organizational robustness including mission clarity and the development of professional staff

Implications

In the discussion above, I have outlined a framework for understanding the factors that lead to robust health statistics systems. In this section, we will consider the implications of this framework for health statisticians' work. Our goal is to identify activities that help determine the extent of robustness.

We have shown that health statistics systems develop over long periods of time yet must respond to rapidly emerging requirements. They traverse diverse disciplinary cultures and serve many purposes. We can focus on key decisions that the compilers, analysts and interpreters must make.

The robustness of a health statistics system will be shaped by how well it can respond to user's needs. This is determined by:

- What it reports
- Pertaining to which populations
- With what procedures
- Through what intermediaries

In view of this, it is not surprising that health statistics are shaped by the content of its compilations, the methods it used to aggregate data, the populations

it covers and its timeliness. Different participants in the social networks that produce health statistics work to shape each of these elements. Constituencies and disciplines play important roles in shaping the outcome of these friendly competitions.

For example, consider the contrast between the prevalence and incidence data collected about cancer and heart disease. Over the past several decades, the National Cancer Institute developed a series of cancer registries [called the SEER program] that record cancer incidence, mortality and survival rates. To do this, NCI analysts agreed that cancer incidence would be recorded as the time of first diagnosis rather than antecedent conditions that were not medically recognized. At the same time, no similar reporting program was adopted for the heart disease field. Rather, NHLBI put its resources into longitudinal studies that trace the factors leading to heart disease. One reason for this decision was that heart specialists have not agreed on a standard for recognizing the moment of incidence. They view the onset of coronary artery disease as progressive phenomena. Any particular event is not seen as a marker of the onset of disease but rather as a part of a long-term problem. They do not have a single assay similar to the detection of cancerous cells that they agree will mark the start of illness.

In fact, cancer is also not as discrete an event as this approach would assume. The distinction is as much the result of the particular approaches taken, as it is a reflection of what is known about the biological factors.

From the perspective of health statistics, we can see how defining when a disease is present shapes the counts we report. These definitions are a product of clinical knowledge, professional consensus and careful delineation of categories. Not only that. They change as knowledge and professional consensus change.

Likewise, the need to provide population data that facilitates integrated analysis of the antecedents of health, health status and care would argue for integrated field procedures. Yet, these are most difficult to construct because they require health statisticians to draw data into a common framework across professional and institutional barriers.

More broadly conceived, our analysis has demonstrated that health statistics systems change over decades, while policy debates rage over months or years. The mismatch between these time frames places a premium on two key activities:

- Analysis that takes advantage of multiple sources of information and
- Institution building that draws from a wider circle of professional and organizational expertise.

The challenge facing health statistics agencies is to meet both of these goals and also respond to their users and the diverse disciplinary perspectives of their critics.