Developing A 21st Century Vision for Health Statistics

Summary of Discussion Group Meetings Held March 9 and May 10, 1999

Prepared for:

National Center for Health Statistics
U.S. Department of Health and Human Services
Hyattsville, Maryland

Prepared by:

Health Systems Research, Inc.
Washington, DC

16 July 1999

Table of Contents

A. Background and Objectives of the Meetings

In 1998, the National Center for Health Statistics (NCHS) joined the National Committee on Vital and Health Statistics (NCVHS) and the Department of Health and Human Services' Data Council in a collaborative process to develop and articulate a 21st century vision for health statistics.

The process is comprised of 4 components:

A Set of Commissioned Papers that would serve to identify key issues in building the 21st century health statistics system, with case examples and international comparisons;

Discussion Groups on Future Directions and a Working Session on Definition of and Criteria for health statistics that would:

— provide an opportunity for brainstorming on future trends in health and health care;

— begin a discussion of desirable characteristics and components of the 21st century health statistics system;

— engage in focused dialogue on the definitions of health statistics, its purposes, roles, and boundaries, and criteria for evaluating the current status of health statistics and the health statistics system; and

— serve as a springboard for discussions at a workshop on *A Health Statistics System for the 21st Century*;

Workshop on a Health Statistics System for the 21st Century that builds consensus on several issues, including:

— defining the field of health statistics;

— the ability to meet data needs;

— improving health statistics resources; and

— developing priorities for building a 21st century health statistics system.

A Consultive Process to Obtain Input on Developing the 21st Century Vision for Health Statistics from a broad base of constituents to assure that the vision is inclusive of a wide variety of perspectives and to maximize consensus and support in the broader community for the end results of the process.

NCHS and NCVHS convened the first of the discussion groups on March 9, 1999 and a second group on May 10, 1999 to address three specific objectives:

> To identify current issues and trends in the health care system that are likely to affect the nature of information required in the early 21st century to respond to policy and program needs;
>
> To discuss the implications of changes in information needs on the current health statistics system; and
>
> To identify the broad parameters for defining and describing the role of health statistics.

The second group was also asked to explore the implications of new technologies on the demand for health data and the ways in which the health statistics system could respond to these demands in the future. A list of participants at these meetings can be found in Appendix A.

The key issues discussed at the meetings are summarized below.

B. Key Considerations in Creating a Vision of a Health Statistics System for the 21st Century

In addition to identifying specific trends likely to influence future health data issues, participants also raised a number of broader considerations that could help provide a context or framework for developing a vision for the requirements of a future health statistics system. These are discussed below.

1. In Defining the Scope Of Health Statistics, Take a Broad View of the Population's Health and Its Determinants

While the charge to develop definitions and criteria for evaluating health statistics had been given to another working group, at different times in both of these discussion groups, individual participants raised the question of what was meant by "health statistics." In addition, other comments were made about whether the term "health statistics" system adequately reflected the types of information collected and activities carried out, or whether others, such as "health data" or "health information" system, might be more appropriate.

The issue of what the best name might be aside, there was a strong overarching sense within the first discussion group that a central focus of health statistics activities should be upon the collection, analysis, and dissemination of information concerning the health of the nation's population and the determinants of health.

The argument was made that health be defined in the broader context of functioning and well-being, rather than in a narrower disease context or on a disease-by-disease basis. The implications of this broader perspective are that a health statistics system should collect and assemble information on measures of health status other than the incidence and prevalence of disease, such as functional status indicators and other measures of the population's well-being.

Similarly, there was general agreement that, while access to and receipt of medical care is an important factor affecting health status, it is clearly not the sole, or necessarily, the most important determinant. A health statistics system therefore should collect and report information on the broader array of factors affecting the population's health status, including environmental and sociodemographic factors.

2. Focus on Goal-Oriented Activities

A number of participants emphasized the importance of collecting health data in the context of meeting specific goals or health information needs. They noted that information should be collected for a purpose, rather than simply because it was able to be collected or "might" be of interest.

One of the important purposes of health data collection and analysis activities that received considerable attention at the meetings was to assist policymakers at all levels — Federal, State, and local — in making informed decisions. Providing accurate and timely information that could assist Congress and other policy making bodies in assessing the implications of alternative policy options on the health of the population and the various aspects of the health care system and in tracking the impact of implemented policies and programs was considered an important goal of the health statistics system that currently was not being fully met.

The implications of meeting this goal of providing useful information for decisionmakers with respect to the nature and timeliness of data collection and analysis efforts will be referenced in subsequent sections of this summary.

3. Assess the Appropriate Role for Federal Health Data Collection Activities in the Context of the Current and Future Market for Health Information

Participants also noted that a vision for the future health statistics system needed to take into account the fact that many different entities, at many levels of government and in the private sector, are currently collecting and using considerable amounts of health-related information and can be expected to do so into the future. They emphasized that the Federal government should examine its future roles, responsibilities, and activities in this broader context and suggested that

a thorough analysis of the full "health information marketplace" would be helpful in identifying appropriate activities. In recommending such a "market assessment, they suggested that questions similar to the following be asked:

> Who is seeking health data? What types of data? For what purposes?

Who is currently producing/providing the data? Who is likely to move to do so in the future?

Will/should State governments play a greater (or different) role in this area in the future?

What might be the appropriate roles and responsibilities for the Federal government in this area?

In addition to sponsoring data collection efforts, the potential roles for a national health statistics agency that were referenced during the meeting included the developer of data standards and the facilitator of appropriate data linkages and integration.

4. Match Data Collection Methods to Requirements

Many participants emphasized the importance of collecting longitudinal data in addressing many of the questions for which the health statistics system will be looked to for answers. Several comments were made that surveys were considered as substitutes for longitudinal data collection, particularly when such longitudinal efforts were not feasible because of funding constraints or other issues. Others noted that, in certain instances, such as when knowledge, attitudes, or constructs can only be collected through dialogue interactions, surveys were the appropriate method.

Another participant emphasized that health statistics data should possess four characteristics: multivariate, multilevel, microdata, and longitudinal. These characteristics are summarized in MC Wolfson, "Social Proprioception: Measurement, Data, and Information from a Population Health Perspective," in RG Evans, ML Barer, and TR Marmor, editors, *Why Are Some People Healthy and Others Not: The Determinants of Health of Populations*, 1994.

C. Key Trends and Issues Relevant to the Design of a 21st Century Health Statistics System

The various trends and issues that participants at both meetings identified as important in shaping both scope and requirements for a health statistics system that will be responsive to the needs of end users in the early 21st century are summarized below.

1. Ecological/Environmental Factors

Many aspects of our environment can have a potentially significant influence on the population's health. These factors and related health indices will be important areas to be tracked through the 21st century's health statistics system.

2. Medical Advances

In general, participants expected that the future would bring a continued flow of medical and technological advances that could have a potentially significant impact on the health status of the nation's population. Among the specific points that were made on this subject were the following:

> The development of new medical treatments will continue, particularly with respect to new technologies and pharmaceutical regimens. However, it will be important to measure the incidence of any unintended effects these treatments may have on patients.
>
> There will be an increasing demand for data that can be used to assess the effectiveness of these new treatments and the impact of the treatments on the health status of the population. Additionally, it will be important to examine the diffusion of these treatments throughout the health care system.
>
> Genetic screening may provide the basis for new targeted preventive health interventions. It will also be important for a health statistics system to track the impact that genetic research may have on the health profile of the population or subpopulations. One participant noted that with the advent of genomics, diagnoses as as they currently exist are likely to become obsolete. For example, he suggested that in the future the diagnosis for diabetes will no longer be simply categorized as Type 1 or Type 2, but rather subdivided according to perhaps 15 to 20 genetic sites at which direct interventions could be targeted.

3. Sociodemographic Trends

A number of sociodemographic trends were identified as having implications for the types of information that a health statistics system of the future should address. They include:

> The aging of the population has implications for, among other things, the profile of illness within the population and the types of services that will be needed and utilized (e.g., an increase in chronic or "maintenance-oriented" care). There will also be an increased emphasis on expanding our understanding of what one participant referred to as "dying" statistics; that is, greater information about the health status of the elderly in their later years, end of life treatment, service utilization, costs, etc.
>
> The increasing diversity of the population with respect to race, ethnicity, and lifestyles will continue to present challenges related to understanding and addressing differences in the conceptualization of "health" across population groups, in the acceptability of health-related messages and health care systems, and in services across diverse population groups. The development, collection, and reporting of measures of health status, disease prevalence, and health care access and use for different population groups was considered to be an important responsibility of a health statistics

system.

Participants also emphasized the need for improved data to better understand and address inequalities in health that result from differences in race/ethnicity, culture, gender, and socioeconomic status. How oppressive factors such as racism and sexism impact health (e.g., negative encounters within medical settings deter use) also needs to be examined. Issues that especially affect immigrants were also cited as important.

The growth in the number of persons who are uninsured was thought to be a crucial marker of the equity of our current health care financing structure and, more specifically, an indication of a possible unraveling of the current employment-based approach to providing health care coverage. Overall trends in these areas will need to be monitored, including the overall number and characteristics of the uninsured and the impact of lack of coverage on their health status. The significant size of this uninsured segment of the population highlights the problem of trying to develop population-based data solely from insurers' and health plans' enrollment-based data systems.

The **nature and definition of the household** has changed over time, such that it is no longer appropriate to look at solely or primarily the nuclear unit, but other household permutations such as grandparents raising grandchildren and single-parent and same sex households.

The "**globalization**" of our society is likely to result in even greater flow of individuals traveling between the United States and foreign countries, a situation that could increase the spread of infectious diseases. Additionally, as this globalization occurs, it will be important to take advantage of the opportunity to link with labs and ministries of health around the world.

4. Changes in the Organization, Financing, and Delivery of Health Services

Considerable time was spent discussing the current state of our health care financing and delivery system, in part because a significant portion of health-related data is drawn from this system. Among the key points made in this area were the following:

The term "health care system" is a misnomer. In reality there is no real system, but an amalgam of elements that are not well coordinated.

Both the financing and delivery elements of the "system" are dynamic and unstable. As noted earlier, one or more participants suggested that there may be a growing interest within the employer community to move from the current system of employers purchasing coverage on behalf of their workers and their families toward a more fixed-contribution approach that would have the individual more heavily involved in health care coverage decisions. Several participants discussed the rapid expansion of managed care in both private and public sector markets and the proliferation of a variety of managed care models, musing about what the “next generation” of managed care might look like. There was discussion about the demise of many “integrated delivery systems,” the frenzy of health plans purchasing one another, and the emergence of only a few large players in some health plan markets.

The trend from fee-for-service to capitated payment has resulted in the weakening of a traditional source of data for the health statistics system. As capitated payment approaches proliferate, the availability of claims or billing data, from which many health care statistics were derived, has been greatly diminished. Encounter data from managed care plans are needed to examine the processes of care that take place within the health care system.

There will be an increasing demand for information about the effectiveness and outcomes associated with not only new treatments (referenced earlier), but existing treatment modalities. The combination of medical advances and rising costs may lead to efforts to make resource allocation decisions about what services and technologies are made available to the general public or covered under health benefit plans. Data that can be used to assess the effectiveness of alternative interventions will be of critical importance in making those decisions.

However, currently cost and competitive pressures have affected different parties’ valuation and use of data for quality improvement and outcomes measurement purposes. Although employers will speak of the importance of the quality aspects of health care in the face of rising health care costs, they may be reluctant to continue to increase their spending in the quest for quality. Indeed, one participant noted that, from an employer perspective, it is difficult to make a compelling business argument for paying more for increased quality.

Additionally, while information useful for quality improvement is valuable to providers and health plans, in some markets where plans are attempting to compete on the basis of quality, such information may be considered proprietary and not shared with outside organizations. However, it was noted that in some markets with significant managed care penetration and considerable overlap in the plans’ provider networks (and in the case of the two examples cited—Minnesota and Massachusetts—the health plans were primarily not-for-profit), there is a greater willingness for plans to share information and collaborate on population-based initiatives.

5. Confidentiality Concerns

With the advent of integrated delivery systems and advances in information technology, consumer concerns about the privacy of their medical information have been heightened. There currently exists a patchwork of different State statutes on this issue, which at times can create significant obstacles in the collection of information for public purposes. As noted by one participant, there are currently 3 bills in the Senate that would change the requirements for informed consent, severely limiting the type of data that can be collected. The nature of the Federal provisions (e.g., whether the legislation preempts or establishes a floor for State statutes) could be an important factor affecting the future health statistics system.

6. Changes in Consumer Care Seeking Behavior

Among the issues and trends in this category were the following:

> There is growing recognition of the importance of "low technology" or alternative health care services and providers. However, one participant noted that, despite the utilization of these treatments and providers, there are only one or two national surveys that even touch on this issue, and that good data on the extent to which alternative treatment providers are utilized, and by whom, are lacking.
>
> There appears to be a trend toward increased self-diagnosis and self-care. Associated with this trend is the increased use of the Internet as a source of information on specific diseases from self-help groups and other sources.

7. New Information Technologies

As the field of information technology continues to advance and these technologies become more accessible to individuals, there are a number of ways in which the field of health statistics will be impacted. Among those noted by meeting participants include:

> Internet use will continue to grow exponentially. It will be important to find a way to target and market to these individuals who desire data and are increasingly more savvy about obtaining them.
>
> Within the next 20 to 30 years, there exists the possibility of supplying "real-time" health and health care data.
>
> Currently, approximately 56,000 retail pharmacies are hard-wired, allowing both the collection of data and the transmittal of information to pharmacists via instant messages. Within the next 10 to 15 years, this technology will be available in physicians' offices as well.
>
> The movement of care out of traditional health care settings and into the home is occurring at a staggering rate. It will be important to develop strategies and approaches to obtaining data for health-related events that take place in the home (e.g., diabetes

and blood pressure home testing).

While one participant suggested that data warehousing and interlinked appliances in the home will become increasingly commonplace, thus accentuating the need for tools that will facilitate measurement of data in the home, another participant felt that this type of technology would not be that widely disseminated, especially among the low socioeconomic population.

D. Challenges/Opportunities for the Health Statistics System of the 21st Century

In addition to the specific issues and trends discussed above, participants at both meetings also identified a number of important challenges and opportunities that the health statistics system of the 21st century will have to address.

1. Articulating the "Public Good" Nature of the Health Statistics System's Activities

There was considerable discussion at the first meeting of the "public good" use of health data. Participants in the first meeting discussed the need to more clearly articulate this concept, issues around privacy and confidentiality which may impede the use of data for public good purposes, respondent burden, and ideas and examples of collaboration.

They agreed that one of the principal problems is that the public good has never really been well articulated. One participant noted that issues regarding confidentiality and shared health information may be a huge impediment to the use of health data for public purposes. Another suggested that in a society that values and places as much emphasis on the individual as does the United States, making a case for the public good concept may indeed be very challenging.

It was noted that Canada has taken a very public view of health care, and the notion of the public good is very explicitly stated and intertwined within the Canadian health system. It was also noted that this may have largely been a result of the overwhelming support for this notion by the Canadian public, who were specifically polled regarding whether they would be willing to contribute their health information for public good purposes.

Several participants noted that the public response might be the same in the U.S. However, they indicated that while most of the population might favor using health information for public good purposes, these individuals are much less vocal than the small percentage who are opposed to the use of their information due to privacy and confidentiality concerns.

2. Addressing New Data Needs

As noted in the earlier section on issues and trends, throughout the course of both meetings participants identified areas or topics on which the health statistics system should collect and analyze information.

For example, one participant indicated that data that will help the public become more informed consumers is needed, noting that the general public is looking for information on how to choose providers (including the qualifications and credentials of individual doctors). However, another participant suggested that information on what makes a difference in health outcomes might be more useful in helping people make informed decisions than is knowledge of individual providers.

There was also considerable discussion on the desire to look at outcomes of interventions and examine the extent to which maintenance care and long term care impact the health care system, all of which require longitudinal data.

The need for more data at the community level was also identified. One participant noted that geocoding, which can now routinely be performed by most health departments, could be one way to address this problem.

Finally, as noted earlier, participants discussed the desire to have more longitudinal data. One participant noted the importance of this type of data in responding to congressional requests, in particular, to make projections into the future (e.g., predicting long term care needs in 2040). Another opined that the likelihood of collecting longitudinal data is very low, especially with the heightened concerns about patient confidentiality.

3. Integrating, Linking, and Aggregating Data Issues and Strategies

A number of participants supported the development of data collection strategies that emphasized flexibility and integration potential. They discussed the need to and added value associated with the ability to integrate data "vertically" (i.e., linking national, State, regional and local data) and "horizontally" (i.e., linking health and non-health data). One participant suggested that it would be difficult to achieve desired integration, especially without a universal health identifier. However, another participant suggested that a great deal of information could be collected from individuals by obtaining informed consent. He suggested the usefulness of pilot projects in collecting this type of information, citing as an example collecting information from an individual when she gives birth or enrolls in a managed care program. Another participant noted that in Canada quite a lot of analysis has been done with the linking of health and non-health (socioeconomic) data through geocoding. He also indicated that Canada is involved in a major review and refocusing of its health-related data collection and analysis efforts, anticipating a shift from about a 90%/10% emphasis on biomedical versus social data to as much as a 60%/40% split between the two.

There was also discussion about the need to provide pathways to link clinical and social statistical data sets. One participant mentioned that AHCPR has been exploring these types of linkages, and noted that the Medical Expenditures Panel Survey (MEPS) is able to provide pathways to link among other data sets.

Another participant noted that efforts to integrate data could begin within individual organizations. He noted that the Centers for Disease Control and Prevention has undertaken a project that will take 11 of its infectious disease surveillance systems (selected by a health systems advisory board) and create a distributive data system. Information will be pulled from each of these systems and linked together.

Another participant suggested that the goals and processes of this process should be promoted as a model that could be replicated in other agencies and organizations.

Participants also encouraged the design of data collection strategies that would allow, to the extent possible and consistent with confidentiality protections, the disaggregation of national or State data to generate community-level estimates, as well as the aggregation of local- and State-level data to generate national estimates.

4. Protecting the Privacy and Ensuring the Appropriate Use of Health Data

During the discussion surrounding the use of health data for the public good and at many other points during the two meetings, participants sparked further comments regarding data privacy and confidentiality. Many participants commented on the fact that the auspices (public or private) under which data are collected and the purposes for which they are used are issues that factor significantly into the data privacy debate. Other comments included:

> One participant noted that even what constitutes the public good can be a very sensitive topic, evidenced by the debate taking place in the Minnesota State Legislature regarding whether medical supplement information contained in the birth certificate should be subject to informed consent.
>
> Another participant noted that the advent of the electronic medical record is an important development for the 21st century. While this soon-to-be-routine approach to documenting patients' health can serve as an important source of data, its emergence raises many data privacy issues, especially as they relate to the transfer of information.

Adequately addressing privacy concerns was considered critical to pursuing strategies to increase the usefulness of data collection activities through data integration and linkage activities.

5. Improving the Timeliness of Data

As participants discussed the types of data that should be collected and data collection issues, they also raised the issue of the timeliness of the data. While participants agreed that, in general, they would like to have more timely data, several opinions were offered about how timely data needed to be in order to be useful:

> One participant noted that the health care system is changing so quickly that there is little confidence in data that are more than one year old. She indicated that her health plan, through a partnership with the State, is engaged in a project to try to improve the timeliness of their data, and suggested that health plans may serve as a better lever to get hospitals to provide more timely data than would States, since the plans have greater purchasing power.
>
> Another participant suggested that how timely and accurate data need to be is very much dependent upon what kind of decisions the data will support. While in some

instances data more than a year old are no longer relevant, in other instances, “older” data may be acceptable for making decisions. A third participant agreed that older data may be able to support decision-making in certain instances, but did feel that a mechanism should be developed to increase the confidence in older data so that they are not immediately dismissed as irrelevant or unusable.

6. Pursuing Public/Private Partnerships and Other Collaborations

Participants at both meetings generally felt that, if the confidentiality of data can be protected, then the sharing of data between the public and private sectors is an area offering significant potential value. One participant noted, for example, that there is no reason why cancer registry data could not be used by health plans for individual case intervention. Participants also indicated that the difference between proprietary data and public data is beginning to blur, with one participant citing an example of health plans using population data from the Medicare web site to target health interventions.

Participants also explored ways in which Federal and State data can be used in conjunction with private data, and the types of linkages that would be useful.

> It was noted that while claims data do not provide information on behavioral risk, this is information that can be obtained from State data. Therefore, linking these two types of data could help improve patient care and serve an important added value in being able to target specific interventions to individuals (e.g., smoking, weight gain during the perinatal period).
>
> An example of collaboration between a health plan and the state public health agency was cited, in which the health plan provided deidentified information regarding delivery (child birth), which was then linked to deidentified birth certificate information and deidentified hospital discharge data. The participant also indicated that as the State continues to build its immunization registry, a similar type of collaboration effort may occur.
>
> Another participant also suggested that as school-based activities grow, the link between school-based health and public health needs to be explored and strengthened.

Several other ideas and examples for public/private partnerships and other collaborations include the following:

> Referring again to collaboration between the health plan and the state public heath agency, one participant described the use of colorectal cancer data on stage of diagnosis to make decisions about changing clinical practice guidelines. She noted that until now the opportunities for this type of collaboration have been few and far between, suggesting that collaborative efforts won’t truly begin to occur until there is a common recognition between [public and private] agencies of the benefits of working together to improve the health of the community.

> Another participant indicated that there is currently a partnership between another state public health agency and a private, community-based organization in which the state agency provides that data, and the interpretation of the data is left to the community organization. Having the community-based organization take responsibility for interpreting the data is one means of ensuring that the interpretation is responsive to the needs of the communities from which the data are drawn.
>
> Another participant indicated that disease management programs provide a good example of public-private partnership. He noted that Merck-Medco Managed Care Inc. has the largest longitudinal data set for diabetes. He also noted the
>
> recent collaboration between Merck-Medco, HCFA, and Veterans Affairs to study long term care and aging.

While the potential benefits of appropriately sharing data between public and private entities was recognized, several participants noted that there may be little interest, if not resistance, on the part of private entities and individuals to collect and/or share information. One participant felt that, except for the research mode of data collection, there is no business reason for payers to collect the amount of data that would be needed by the health statistics system, and commented on the opposition payers may have in funding these collection efforts. However, several other participants disagreed, suggesting that data are needed to help physicians better provide services to patients.

There was also discussion surrounding the burden that existing and additional data collection activities place on the respondents. It was noted that while physicians might not mind providing information (via survey or questionnaire)—especially if they were receiving feedback on how to improve their performances—they might be less willing to be a part of these data collection efforts if they were asked to take part in numerous efforts. Another participant indicated that she is finding it harder to get individuals to respond to data collection efforts, and noted that she was unsure of whether individuals were just too overburdened with data collection, or whether they had concerns regarding what would happen to the information they were imparting.

Participants also discussed collecting data from patients as an alternative to gathering it from physicians. One participant noted that without input from physicians, they have to try to collect data directly from patients, which is both difficult and costly. She noted, however, that not collecting this data may turn out to be more costly in the long run.

Several participants suggested ways in which to promote access to information, particularly from health plans. One participant noted that some States are contracting with health plans to provide data (e.g., CHIP) as part of the capitation payment they receive for providing services to enrollees. Another suggested that what could be done is to build in the expectation that data be made available, especially if it can be provided at a modest cost to the plan. A third noted the need to also be able to ensure that there are some kind of quality standards on the data if they are provided by plans in this way.

At the second meeting, another participant urged that some form of value-added feedback loop be established to provide incentives for health plans, providers, purchasers, etc. to share data with the public sector health statistics system. For example, the interest on the part of these entities to provide the health statistics system with data that would then be combined with other data (e.g., relevant National or State health data or other sociodemographic data) likely would be increased greatly if, in return, they were to be provided with either a copy of the linked data file or other types of feedback information (e.g., some form of standardized report cards).

7. Developing Data Standards

Participants at the second meeting discussed the need for more standardized data, the value that standardization could have in promoting integration and linkages, and the valuable role that the health statistics system could play in developing and promoting such standards. Some of the specific areas cited during the discussions as being in need of standards included:

- Administrative data (including those from public systems and health plans);
- Race/ethnicity classifications;
- Definitions of households;
- Gender classifications; and
- Geocoding.

8. Adapting to the Wider Availability and Use of Health Data

With the advent of information technology like the Internet, the public has a greater degree of access to health data than ever before. The meeting participants discussed the changing role of the media, advocacy groups, and the general public in the use of health data, the implications of wider data availability, and strategies for dealing with these changes. Among the key issues discussed were the following:

Media and Advocacy Groups

Several participants talked about the changing role of the media, and the fact that the media (in particular, television news programs, newspapers, and magazines) now have full time health care analysts on staff to try to meet the growing demand

for information on health and health care. One participant noted that these “health reporters” are now the counterparts of health statisticians, indicating that more reporters will find ways to use health statistics than in the past, and with an increasing amount of sophistication. Another participant noted that in addition to the media, advocacy groups are also using health statistics. Many of these groups are looking for the data without any analysis, figuring that they can perform the analysis themselves.

Implications of Wider Data Availability

Many participants felt that a key issue associated with greater access to data is the unwillingness of end users to go through gatekeepers, instead going directly to the source of the data without consulting “experts” for any type of analysis. They noted that this not only makes it a lot more difficult for the "experts" to remain in the loop on how the data are being used, but increases the potential for misuse or "incorrect" analysis of data, since these new users of data might not fully understand the caveats or complete uses of the data.

Concerns were also expressed about the reliability, validity, and completeness of data that are made available to the public.

Strategies for Dealing with these Changes

Participants agreed that it is not a question of whether data will be publicly available, since access to this type of data will surely increase, but rather how to help people use the data better and more accurately. Several strategies were offered for dealing with this issue, including:

— **Providing reporters and consumers with data in a way they can readily use**, including using lay terms that explain the caveats of the use of the data, along with some data analysis.

— **Making data available through the Internet** will help meet increased media and consumer demands. One participant noted that while this approach may increase the risk of misuse of data, this risk should be taken, and that perhaps people will pick up on the misuse/bad reporting of data and conduct their own data collection activities.

— **Building intelligent systems** so that people can make better use of the data. One participant indicated that he would like to see the government statistical system invest more in this type of effort, working in collaboration with the computer science community.

E. Suggested "Action Steps"

Participants at the second discussion group concluded the meeting by suggesting a number of action steps that could be taken to inform and move forward the development of a 21st century health statistics system. Some of the suggestions put forth include the following:

Promote the public debate of health statistics issues. Develop questions/issues (e.g., the inequality in delivery and measurement of health and health care) and make them available for public comment, similar to what was done with Healthy People 2010.

Improve constituent input and support. Suggestions in this area included:

— **Institutionalize the input of organizations** like the National

Governors' Association (NGA), the National Conference of State Legislatures (NCSL), and the Congressional Budget Office (CBO) so that questions/issues that need to be addressed can be continually remarked upon. Also include foundations, especially the Robert Wood Johnson Foundation since it is large and has an interest in this area.

— **Build a public constituency** within the field of health statistics that can make its opinions heard. In order to build this constituency, the health statistics community needs to be able to answer the questions that people are asking. However, it was noted that public agencies have to walk a very fine line between providing data that people need and taking a biased approach to data collection that might offend other groups.

— **Informally poll people** for the issues they think are compelling and collect/provide those data.

— **Enlist the support of the originators of big initiatives** (e.g., Elimination of Racial and Ethnic Disparities in Health), since these initiatives are likely to need data support their efforts.

— **Bring in those who generally aren't included** in the discussion of health statistics issues such as advocacy organizations, so that their unique needs can be addressed and their connections with policy makers can be a part of the process.

Assess the data that already exist and develop ways of widening their availability/use. There is a tremendous amount of data that have been collected, but much more could be done to make these data more available. A suggestion was made following the second meeting that an on-line compendia of data systems that comprise the health statistics system in the country be developed. Descriptions of the data sets would be provided (including sample or population size, units of observation, and data elements) rather than the actual data.

Consider the creation of a center for "data gnashing." This center would operate somewhat like a think tank, and would come together, perhaps on a quarterly basis, to talk about relevant actions/events that have taken place.

Build support for the sharing of data within the health statistics community. This is particularly important because there are people within the industry who should be invested/interested, but don't have confidence that the data won't be used for nefarious purposes or that the confidentiality of the data will be protected.

Begin the development of value-added feedback loops to promote public-private and public-public data sharing/integration. Pursue partnerships with purchasers, health plans, provider organizations and other entities that have useful information to allow appropriate access to their data in return for linked data or analysis that would be of value to them.

Continue to pursue, in collaboration with others, the development of data standards, including definitions for data elements, minimum data set specifications, etc.

Appendix A. List of Discussion Group Participants

Ross Arnett
Agency for Health Care Policy and Research

Linda Bilheimer
Congressional Budget Office

Lisa Broitman
National Center for Health Statistics

Kathy Coltin
NCVHS and Harvard Pilgrim Health Care

Donald Detmer
NCVHS and University of Virginia

Jane Durch
National Academy of Sciences

Stanley Edinger
Agency for Health Care Policy and Research

Robert Epstein
Merck-Medco Managed Care, Inc.

Judy Feder
Institute for Health Care Research and Policy, Georgetown University

Daniel Friedman
NCVHS and Massachusetts Department of Public Health

William Friedewald
Metropolitan Life Insurance Company

Marsha Gold
Mathmatica Policy Research

Marjorie Greenberg
National Center for Health Statistics

Edward Hunter
National Center for Health Statistics

Larry Kessler
Office of Surveillance and Biometrics, CDRH, FDA

Nancy Krieger
Harvard School of Public Health

Laura Meckler
AP Wire Service

Dan Melnick
Dan Melnick Research Incorporated

Len Nichols
Urban Institute

Ellen O'Connor
Washington Business Group on Health

John Oswald
Minnesota Center for Health Statisttics

Jonathan Peck
Institute for Alternative Futures

Dorothy Rice
Institute for Health and Aging, University of California

Linda Rosenstock
CDC/NIOSH

Jim Scanlon,
Office of the Assistant Secretary for Planning and Evaluation, DHHS

Edward Sondik
National Center for Health Statistics

Barbara Starfield
NCVHS and The Johns Hopkins University

Miron Straf
National Academy of Sciences

Steve Thacker
Epidemiology Program Office/CDC

Thomas Thom
National Heart Lung and Blood Institute

Kathy Wallman
Office of Management and Budget

Robert Weinzimer
National Center for Health Statistics

Michael Wolfson
Institutions and Social Statistics Branch, Statistics Canada

Donald Young
American Association of Health Plans

Jennifer Zelmer
Canadian Institute for Health Information