

21st Century Health Statistics Vision Process
National Center for Health Statistics (NCHS) Meeting Summary
October 15, October 18, and November 19, 1999

A. Introduction and Background

On October 15 and 18, and November 19, 1999, discussions were held among NCHS staff who volunteered to participate in the 21st Century Health Statistics Vision Process. These discussions were loosely organized around questions posed in the “Pre-Meeting Preparation Workbook” that was distributed to all NCHS staff in early October. Not all of the questions in the workbook were covered; nor did the discussion neatly flow in order of the questions. Given that, to the extent possible, the summary below of the discussion is organized by the response to each question:

B. Major Current and Emerging Health Issues

1. What are some of the major trends in health status of the U.S. population in this decade? (e.g. chronic conditions, disabilities). Do you see these trends continuing into the next decade? If not, how will they change?

As people are living longer and the *elderly population is growing*, issues with health of the chronically ill, long-term-care and end-of-life care are prominent.

Too many people lead a *sedentary lifestyle*, and the increase of technology may bring a decrease in physical activity among some; and not all physical activity is equally beneficial, i.e. construction workers may get lots of exercise, but not of a cardiovascular nature.

Technology has contributed to the *increase in multiple births and in low birth-weight births*. While technology keeps more low-birth weight babies alive, it also increases health care costs.

We are witnessing the *re-emergence of diseases* we once thought were no longer problems, i.e. tuberculosis, rabies, certain infectious diseases.

There is renewed concern about the *public health infrastructure*; systems we long ago forgot about, such as sanitation, are becoming important again.

With the growing diversity of the population, there is a need to look more closely at *disparities in health and health care*. We need to know more about the health of immigrants and the homeless.

There is concern about *child health*.

There is also concern about the *health of the disabled*. It was said that disability is moving from a strictly medical issue to a social issue. Disability varies by age, and we need to especially look at disability of children.

Violence was cited as a public health issue of importance, and it was said that we need to look at its effect on families of victims. Sub-issues of violence also need to be considered, including suicide, homicide, and verbal violence—and there are definition issues associated with these.

More generally, it is necessary to look at the *health of families*, including the “sandwich generation” and care-givers of the unhealthy. There is concern about the safety and the training level of non-professional care-givers.

Air pollution, water quality and other *environmental issues* are of concern. It was said that more local area data are needed to adequately measure exposure to environmental hazards, and that this raises methodological and confidentiality issues.

The question was raised by discussants as to how we *define and measure health*. We tend to define health as the absence of disease; we don't study health, but the lack thereof. What is it that makes people healthy? And how do we measure quality of life? People's expectations of what is acceptable health is changing. Advances in human genome research may bring changes in what we think of regarding health status; it may also change how we view race and ethnicity. There is a greater focus on the behavioral role in conditions; however, there is not always an apparent payoff in health status even with awareness of the importance of behavior changes.

Other topics mentioned in the discussion on health trends:

- an increase in asthma;
- stroke is not decreasing;
- a decrease in tobacco use;
- little change in cancer outcomes;
- there is an increase in overweight; and
- AIDS remains a serious problem.

2. What are some of the major trends in use of health services and delivery of health care in recent years? (e.g. managed care; physician group practices; migration of encounters to outpatient settings). Do you see these trends continuing into the next decade? If not, how will they change?

Influences on Health Care System

Advocacy groups are increasing for people with specific diseases, and for people who share other characteristics (ie. gay/lesbian groups).

Industry and the media are increasingly influential on health decisions. The Internet has brought increased access to health information, and there is a trend toward health care delivery over the Internet.

Provision of Health Care

Self-testing and self-care are becoming more common. Baby boomers expect instant access to information, and are generally taking a more direct approach to health care; they tend to be “armed” with data, and will make their own demands of the health statistics system.

Use of *outpatient facilities* is increasing, as well as home health care, rehabilitative services, and continuous care (assisted living) communities.

Specialized clinics are increasing, such as the MDA centers for treatment of ALS.

Community-based services for the elderly are becoming more popular, including senior centers and other services that are used by healthy older Americans. We currently do not have good measures about these services.

Fewer providers of care result in less competition; large hospitals are “buying up” satellite sites in rural areas, and there are multiple specialities in single locations, providing “one-stop-shopping.”

At the same time, we are seeing more *compartmentalization of care*—specialists for each ailment, rather than more holistic treatment of the individual. One discussant noted a trend toward a new type of health provider, a “hospitalist,” who takes over the care of a patient from the primary care-giver once the patient is hospitalized.

Separate billing for every service, with no coordination, is common; at the same time, patients are resisting the coordination seen in managed care.

Some feel there is a *failure of delivery of services in nursing homes*; nursing homes expect families of patients to provide most of the care-giving. There are concerns more generally about standards of care, including questions about proper ratios of patients to staffs.

Emerging Medical Treatments

Measuring the *effects of emerging medical treatments* is necessary; for example, how will patients of laser eye surgery be doing in 15 years and whose role is it to monitor that?

Non-Traditional Health Care

Alternative health care is gaining attention, including acupuncture, spiritual healing, etc. It was said that 15 years ago, researchers at NIH couldn't even mention the word “chiropracting,” and now there is an entire group there devoted to its study.

While there is set of *defined records* for hospitals and other facilities, that is not the case for sources of non-traditional care.

There are also *licensure issues* with non-traditional care providers.

Cost Concerns

There is increasing *pressure on the health care system* to make health care delivery more efficient and to contain costs, and this will require “tradeoffs” on where to distribute dollars, and will have a major effect on the delivery of health care.

Service delivery-demand will continue to grow with the aging of the population—with increased pressure on medicare and other insurance to cover increased costs.

Data Issues and Confidentiality

A *standardized computerized patient record* is desirable, and with it the concern about keeping private information out of hands of government and business.

Mental Health

Mental health service delivery is changing. More mental health counseling is being provided by telephone, which is bringing greater access to rural areas, but is also raising privacy concerns.

Administering of *medication for mental health diagnoses*, especially to children (versus counseling therapies), is increasing.

Social health are gaining attention, including issues of alienation that contribute to events such as Columbine. It is more common to find guarded communities, where residents lock themselves off from the surrounding population. This creates an obstacle for interviewers trying to survey sample respondents.

Workplace Health

Workplace health is increasing in importance and there is increased delivery of health information through the workplace.

Genetics

In coming years, more *genetic therapies* will be developed, as we look at agents that cause disease and how we can change them or the genes they operate on.

As more information becomes available about *genetic risks*, changes will occur in the system for insuring people. We may not be able to use a risk-pool approach to insurance; and there will be concerns that information about a person’s genetic risk will be discovered by a potential employer who will use the information to rule out job candidates.

There is concern that *genetic testing* will provide a great deal of information about a person’s risks, but that there will be little that can be done to lessen these risks.

Impact of Social Changes in U.S. Population

The *transient nature of the U.S. population* is a concern, as well as its impact on the health care system. With our mobile population, it is often the case that people see a given health provider for a very limited time before moving on to another one, creating fragmented medical records and raising issues about confidentiality where there are efforts to track individuals over time.

Also with our mobile population, there is concern about how care-givers can manage *care for family members* not living nearby.

Border health issues are a concern, including people coming into the U.S. for care, as well as U.S. citizens seeking care outside of the country. It was said that the number of Americans living outside the U.S. is growing, and that the U.S. health care systems does not adequately cover their care.

3. What will be the key technological considerations for the health statistics system and for health information more generally, in the next several years? (e.g. the Internet; health informatics).

We are becoming an increasingly “*wired society*,” and technology will have a major impact on how we collect, analyze and disseminate information as well as how we provide medical treatment.

Technologic Development

Technology will permit *more rapid data collection*. It will aid in identifying population subgroups and in collecting data on them.

Internet technology will be used to select samples and electronic kiosks will be utilized to collect data. Systems such as CAPI will become more prominent. We will be able to use computer simulations for many areas of data that remain stable.

The capability to *store vast amounts* of data gives us the ability to “tap into” the wealth of information from the whole “stream” of information from administrative records. Thus we may not need to conduct large surveys and to create databases to obtain information.

Computerized clinical records may soon provide data equivalent to that on birth certificates. For example, the Mass General birth information system could replace the vital registration system for births. This raises issues of data standards: if in the future there isn't a birth certificate, how can we be sure we'll still get all of the information we need in the way that we need it?

Technology will make it easier to *share information across the medical system*. But advances in technology also heighten concern about privacy; with more people accessing data, how can we ensure the security of data systems. Can solutions be found that allow individuals to choose whether or not to provide access to their medical information (versus mandating access)?

Technology may increase “opportunities” for *survey non-response*; people with “caller ID” for example, can screen out telephone calls from survey interviewers.

Public Access to Health Information

The *way consumers obtain health information* is changing. Technology permits more rapid access to information. Individuals are getting information through Internet sites such as Dr. Koop’s.

Advances in technology will allow users to enter into *confidential systems* that would return data specific to them—they will be able to obtain a health profile that will give them information to help make personal decisions. They will be able to contract with new companies that can serve as their “agent” to hold all of their health data, automatically access their record as needed (i.e. for prescriptions, etc), and monitor their interests.

Using Technology to Address Health Issues

Technology is getting *new treatments* to the public more rapidly. Technology can be used to obtain more rapid approval of medication and other treatments through FDA. More medications are being distributed to consumers through the mail.

Technologies are producing “*designer foods*” that can provide various health benefits.

Technology is producing new *invasive and non-invasive tests* to monitor health. Several concerns were expressed about these tests: not all patients have equal access to them, patients do not always know which of these tests are actually conducted on them, some of the tests have very high costs, and there are questions as to the usefulness of these tests.

New technologies are being developed to automatically administer *pharmaceuticals* to the body—in specific doses based on individual needs-- and to perform other functions. One example is the trans-dermal insulin pump that can measure need and inject insulin as needed.

In the future, there may even be an individually bar-coded “*statistics chip*” that can be implanted in individuals to monitor functions and provide needed remedies .

4. What developments do you foresee in statistical methodology in the next decade, and what affect will they have on the health statistics system of the future?

Measurement Issues

OMB’s changes in racial and ethnic classification will have an important impact. With changing definitions, how will we get population estimators for our denominators? How will changes in definitions affect our ability to monitor trends in illness and use of health services?

The move to *ICD 10* will present measurement issues.

The *measurement of disability* also an issue.

Methodology

Methodologies for *data dissemination*, as well as data collection and analysis are changing.

With changes in methodologies for *data collection*, analysis and dissemination, comes the need for periodic evaluation of how well new methodologies are working.

Data Issues

Data standards are increasingly needed; there was concern that data standards will be set by external organizations.

Linkages are needed among datasets.

Dissemination of Health Data

The audience for health statistics is changing, as people access information over the Internet, and this requires new methods to disseminate information in ways these new audiences can understand and retain.

The discussion about technology (in Question 3, above) identified methodological challenges, with use of computer simulations and enhanced sampling techniques to collect information, including sampling via the Internet.

5. How will any changes you foresee in demographics and social policy in the next decade affect the health care system? (e.g. aging and diversity of the population; welfare reform).

The *aging, increased diversity, and mobility of the population* are discussed elsewhere in this summary.

Another demographic change mentioned was the *change in family structure*. What is the effect of divorce and separation on who cares for whom in families? Will changing families structures contribute to more difficulty finding time to respond to health surveys? What is the impact of same-sex marriages on health insurance and access to care?

C. Health Information Needs Associated With Trends

6. What will be the information needs for addressing the issues that you identified above? On the national level? State? Local level? (Consider both public and private sector needs.)

General Data Needs

We need:

to look at *behaviors and other risk factors* affecting health, to study the relationship of genetics and health, and to try to get at the root causes of diseases;

why some people are able to *avoid health problems* and what can we learn from them, rather than only studying the unhealthy.

to identify *methods of modifying risks* through education, through environmental changes, and through a focus on quality of care and outcomes of care;

a *database of information* about people's health care to help measure quality of care. This includes a "report card" for HMO's as well as more study of practitioners of less traditional medicine. All of this must be done in such a way that protects patient privacy; to look at "*health*" *very broadly*—to study such interactions with education, justice, housing, and the environment;

to study *vulnerable populations*—the homeless, immigrants, aged, rural, and racial and ethnic groups. We need to start by obtaining adequate baseline data on special populations. This requires agreeing on standardized terms to know who we're measuring, and to look at various methods such as dietary pyramids for racial and ethnic groups, to help understand disparities;

to be able to *compare data* collected about the civilian non-institutionalized population with data on veterans, the military, and the incarcerated population; and

more information about *pharmaceutical use* on a person-basis, and for information about "nutra-pharmaceuticals."

Providing Data to the Public

We need:

to provide information in *reasonable and understandable formats*; to educate users about information resources and to provide training in their use;

to help consumers determine "*what information on the web they can trust*,"

to address concerns about *ethical abuses of statistics* by researchers; poorly designed surveys that purport unsubstantiated findings waste money, damage public trust, and result in decreased survey response; and

to be sure that there is *widespread access* to computers and other resources. It was stated that it does no good to make information available if people can't access it.

7. How can the health statistics system of the next decade and beyond, respond to those information needs?

This was discussed in the context of other questions and responses are reported throughout this summary.

8. Do you have specific examples of how information has been—or could be—used to contribute to health care and health policy making, program development and research?

This was discussed in the context of other questions and responses are reported throughout this summary.

9. Who are some of the key users of health statistics information and how might we go about gaining their input into the above question? Please identify any specific individuals or organizations that should be involved in this process.

Several groups were identified, including:

AARP and other representatives of the older population;

the business community, such as market research departments, trade associations, AT&T and other major employers, Fortune 500 businesses, private health consultants, software developers, manufacturers of medical supplies, dress manufacturers, car manufacturers, drug companies, and food companies;

“front-line” providers of services at the local level, such as educators, social workers who work with children;

state and territorial officials and local government officials such as county managers;

insurance companies, such as Aetna, which collects information about dangerous intersections;

congressional staffs, which need to be educated about our capabilities;

sports organizations;

foundations;

medical organizations;

teacher associations; and

the NRA.

Suggestions were made to utilize several listservs, including those of the NCHS Minority Grants Program, National Health Interview Survey, HIPPA, and NCVHS. The question was raised as to whether this might result in more feedback than we are prepared to address.

10. Given your response to all of the above, what would you consider to be the highest priority needs to be addressed in building the health statistics system of the future?

This was discussed in the context of other questions and responses are reported throughout this summary.

11. What do you think NCHS should do—in the short-term and in the long-term—to prepare itself for meeting future needs?

Survey Design and Data Collection

NCHS should:

have *shorter design cycles* for our surveys, and more integrated surveys.

be *more analytic* in decisions about what information needs to be collected.

have more *flexible surveys* that can supplement our larger surveys with information about targeted populations, such as we're doing with population-HANES and SLAITS, to supplement NHANES and NHIS.

collect *person-based statistics*, with repeated follow-up through longitudinal studies.

do more *methodological research*.

take better advantage of *GIS methods*.

allow *ORM* to have a greater role of looking at other methodologies, as its role has traditionally been to support existing surveys. Others suggested that this has to happen outside of NCHS.

do more *cognitive work* to help address non-response; we need to know more about reasons for non-response from individuals to our surveys as well as from organizational entities such as hospitals.

Data Collection

NCHS should:

play a greater role in developing *data standards*.

have better *metadata* to understand what it is that is being collected.

capitalize on its *reputation as unbiased source*—we should move from being a trusted “source” of information to a trusted “probe”, whereby we “dip into” various information streams to obtain data.

include data from other sources in our own analysis.

include *claims data and other administrative records*. This requires us to address political issues of access to administrative data—proprietary versus public “rights” to

data. NCHS should focus on technology for data collection, analysis and dissemination—this will provide us with the best chance of responding to changes in health status and health care delivery.

NCHS Outreach

NCHS should:

think of its *role more broadly*—we “do” health statistics, but we’re also part of the overall assessment process with other public health agencies—we need to think of it as a process, not as a stovepipe.

expand our *centers of excellence*, promote research data centers, and take a greater role in bringing state and local data together.

invest in working with state and local governments and with the private sector. We tend to serve researchers and policy-makers, letting them tell the public what information they “need” to know; we should look at the general public as our audience, too—to provide our data in a format that’s useful, understandable, organized.

help *state and local governments* do the same at their levels. We should provide state and local agencies with training in technologies for data collection, analysis and dissemination.

work with the *private sector* to increase the value of information resources for the public.

Internal Processes

There were several suggestions for improvements in internal processes within NCHS, and for additional data collection activities. NCHS should:

do a better job of coordination and information sharing within the Center. Problems of comparability were noted; we need agreement on using the same measures.

address the issue of collected *data that is not disseminated* because of confidentiality issues.

improve the accessibility and cost of the *data research center*, an important resource.

make tradeoffs and develop priorities for release of data; one example given was the need to choose between trying to provide data at state and local level versus looking at urban versus rural “cuts” at our data (with the potential for identification too high if we try to do both).

provide more *functional status information* and related it to quality of life.

enable the *website* to evolve to meet new information needs. We should do a better job of “advertising” our data on the Internet to show the usefulness of the information we

collect.

do a better job of “*selling*” sample people on the value of our surveys.

collect *demographic data* about health providers and look at how that matches up with the population they serve—and to measure the impact on the health of patients to have providers with demographic backgrounds different than their patients.

do *methodological research* on race and ethnicity and must do it in such a way that provides useful information and prevents misuse.

study *how patients learn to work their way through the health care system* to get the care they need.

identify *data needs*—some of which are data gaps—without getting “hung up” on “turf” issues.

periodically *review priorities* we set.

provide more *global leadership*.

provide more *training* within NCHS—through employee exchanges and cross-training programs.

12. What issues not addressed in the above questions, need to be considered in building the future health statistics system?

This was discussed in the context of other questions and responses are reported throughout this summary.