21st Century Health Statistics Vision Process
Albuquerque Meeting Summary
March 1, 2000

A. Introduction and Background

Below is a summary of a discussion session held in Albuquerque, New Mexico on March 1, 2000.   This session was one of several discussions with state and local collectors and users of health data, as part of the process of helping to shape the Nation's health statistics system for the 21st century.

The process is beginning with a dialog on future health and health care trends, information and communications technology, and public policies. By its end, this process will:

> identify forces that will shape health information needs and opportunities for the future; and
> will formulate a vision for the future that will help guide policy and planning for health statistics programs.

The process is a partnership of the National Center for Health Statistics, the National Committee on Vital and Health Statistics, and the HHS Data Council. This discussion was loosely organized around questions posed in the "Meeting Preparation Workbook" that was distributed to participants prior to the meeting.   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 below summary of the discussion is organized by the response to each topic area.

B. Major Current and Emerging Health Issues

1.   **Identify major trends in health status of the U.S. population in this decade (e.g. chronic conditions, disabilities).   Are these trends likely to continue into the next decade? If not, how will they change?**

Defining Health

> While trends in health status were identified, the discussion really focused on the *need to define health status broadly*, and to consider the social determinants of health, not only medical care.

> While *health in a broader context* is not being considered, importance of prevention is recognized. We must include social and economic issues when we talk about lifestyle; practicing prevention is not just an individual choice–not all people can afford healthier behaviors.

> We aren't very good at *determining health status*–we tend to "look in the rear-view mirror."

> *Individual-level data* and individual-level solutions tend to be considered. This often

masks the context, making it difficult to develop broader intervention strategies.

Resiliency and "protective factors" are not measured as well as health risks and "events."

The *relationship between behavioral health and physical health* should be researched. The trend seems to be going backwards–swinging back from behavioral health to medical care.

The *relationship between education and health* must be considered – many illnesses could be prevented with education.

Infant and Child Health

Risk factors and morbidity for infants need to be better understood–we place much emphasis on infant mortality, but we also need to look at those infants who survive.

Quality of life issues, especially for children with special needs, need to be considered.

Good *definitions for child health* are needed, as well as more about children with special health needs.

More data about children in general would help formulate future health policy.

There is an *increase in medication use* for children–some children are taking Ritalin by age 4.

Adolescent health is a concern, especially the lack of physical activity. Schools require almost no physical education anymore; we need to develop a culture where physical activity is valued.

The *attention span* of children and adolescents is decreasing.

Reading levels should be seen as health status indicators.

Other

A relationship between *environmental exposures and health outcomes* exists, and we need to look at health in the context of the environment.

There is a increase in the incidence and/or diagnosis of *mental health problems*. There is a move from viewing mental health as an individual, emotional problem to viewing it as a medical problem, since it is being treated more by medicine.

There is an increase in:

> incidence of diabetes-type II in younger populations, especially among Navajos and Hispanics;

autoimmune diseases; and
multi-drug resistant strains of infectious disease.

2. **Identify 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).   Are these trends likely to continue into the next decade? If not, how will they change?**

Quality

There is a trend toward much *greater accountability through data*–from beginning to end.

People expect *service quality*, and no longer accept that their physicians are all knowing.

We see ourselves as *customers* rather than simply patients. And we expect service quality (improved waiting times, etc.) as well as clinical quality.

But there is an *"information/empowerment differential"*–some people obtain a great deal of information over the Internet before seeing their physician, while others go to their doctor without having such information. There is concern about the ability of the health care system to meet expectations based on old models of care.

More information about *medical effectiveness* is needed: what <u>is</u> effective treatment? And when we <u>do</u> have information, there is a need to <u>use</u> data to help guide treatment.

Alternative Medicine

Use of *alternative care* is increasing, as well as "treating the whole body;" but there is a lack of good information about the quality of homeopathic remedies and alternative drugs.

We need to know more about behaviors in *use of "traditional" prescription medications* as well.

Medical Errors

The health care industry is starting to be viewed like other industries, in terms of *accountability for errors*.

Good information does not exist about the problem of medical errors in health care industry, and thus end up with decision-making based on anecdotal information or hyperbole.

A culture that supports the *reporting of medical errors* is needed, but privacy issues complicate better tracking of medical errors.

Access

There is a question of *health assurance*: having coverage does not always mean care is actually received.

There is concern about *tiers of service in HMOs*.

Health costs are rising, and costs for the elderly are rising beyond what Medicare and Medicaid will pay. How will we be able to pay for all of the new pharmaceuticals that are being developed? How will the elderly pay for eyeglasses and dental care that are not covered by insurance?

Information about *patterns of access to care* needs to be better captured. For example, we don't know enough about people who migrate out of their county to fill a prescription, for fear of disclosure of AIDS.

Boundary policies can sometimes restrict Native Americans on where they can go to access care.

The emergency room is where many people with limited English-speaking ability and those with immigration issues access health care.

Prevention

Secondary prevention is forgotten with so much focus on primary prevention. And we look at prevention only in the short term.

Prevention long-term and community-wide needs to be addressed, and recognize it takes a long time for behavior changes and for prevention benefits to surface.

The *medical system is disease oriented*, not health oriented.

Western medicine and alternative medicine need to be compared and why people choose one over the other needs to be determined. A strong point of Oriental medicine is prevention. But managed care allows Oriental medicine only for pain management (short-term). We need to think of "health" more broadly; not only as the absence of disease. We need to understand that emotional, spiritual, and physical health are all related.

Health Care Delivery System

Some see a shift from health improvement to *corporate money making*.

We expect to have more say about our health care, but with the *financing structure*, we actually are less empowered.

Managed care has made care less accessible–we may have to wait months to see a

physician for non-urgent care; while we can get access to providers not covered by managed care, such as acupuncturists, right away.

There is an increase in the *uninsured and underinsured population*. Some say we are moving closer to universal health care, and point to the increased attention the issue is receiving in the Presidential election.

Rationing of health care already exists, though it is not discussed.

There are *mismatches between contributions to the health care system with health care needs*; for example, farmers, ranchers and other private entrepreneurs who haven't paid into the system won't be eligible for care when they get older. (THIS STATEMENT NEEDS CLARIFICATION, PLEASE)

Genetics

Mapping of the genome has major implications. The genotype will redefine health status, and may result in the demise of risk-based insurance.

We will have the ability to identify more and more risk factors for disease without being able to do anything about certain risks.

New universal newborn screening programs screen for many disorders and people are getting tested and categorized even before a disease is identified.

Other

There is *increased health information and health care provided over the Internet*. People are receiving care through "Web MD" and other services. And sometimes people use data received over the Internet without knowing how to do so correctly.

Demand for input from health consumers into their care is increasing; this applies not only to individuals, but communities as well. We say we want community input, but do we use it when we get it? What the community says it needs is often not what we think of as a public health issue.

Care from *midwives* is not reimbursed.

3.   **Identify anticipated developments in demographics and social policy in the next decade, and how they will affect the health system (e.g. aging and diversity of the population, welfare reform, etc.)**

Socio-Economic Status

Economic inequality is rising; the relative disparity between rich and poor is growing in terms of health status, as well as access to health care.

The intersection between *employment and health status* and health care is important.

Comparable outcomes for racial and ethnic groups need to be assured.

Violence

Problems of violence, poverty, and other social and economic issues need to be resolved if we are to improve health outcomes.

Gun violence is a health issue.

Physical violence is an issue for pregnancy health.

Minority Health

A *"minority outcomes"* report card would help measure status.

A distinction is needed between recent *immigrants* and the long-term, native minority population.

Other

The *definition of the family* is changing, and we must look at health status in the context of the family.

Ethical issues in health need to be addressed, including end-of-life issues.

Better *rural health data* is needed; we used to have more information about rural health and now we can't find data that fits the rural population.

The *population is aging*, and there is a need to better manage chronic disease.

Community-based services are increasing, such as school-based wellness sites, which is a welcome development; but costs for this care are not reimbursed, and this puts a strain on public services.

Doctors in rural areas are decreasing.

C. Health Information Needs Associated with Trends

1. **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.)**

Data Needs- General
The following are needed to improve the data collection systems:

More timely data from existing data sources is needed. Technology may offer the opportunity for more rapid data collection and release.

It is important to *find ways to dispel distrust about how data will be used*. This can be done by making data collection relevant to the population of study, and <u>include</u> them in the process.

C*ontinuity in the multitude of reporting systems* is needed, so that we can combine and compare data from multiple sources. We need to know, for example, how many people are eligible for food stamps versus how many are receiving foodstamps.

Understandable and user-friendly data and reporting requirements are needed.

Data standards and linkages are needed. Even databases housed in the same organization cannot be linked, since they were created under different mandates.

Research and evaluation methods should focus on *qualitative factors* –not to simply look at "the numbers."

We must be able to *look more broadly at the complexity of health needs* and health outcomes.

Interrelationships should be considered more extensively; we must stop looking at health issues as "silos." For example, how does alcohol abuse relate to domestic violence, and what is the connection between domestic violence and use of health care services. Research is too frequently based on "linear thinking"–we need to look instead at health needs in the form of a flow-chart or matrix.

There should be *more emphasis on what works*, what's effective, and what we're learning–not just present information about health risks.

There is much opportunity to take advantage of *"group" data created by HMOs*. We should use these data from HMOs to learn what works for populations. And it would be valuable to merge data for people in HMOs with information about those not in managed care, to gain a more "global" picture. It is understood that concern about identity fraud complicates data sharing.

Data with *an "economic impact tag"* are more "primed" for policy action –if it compares the cost of taking action to address a health problem with the cost of <u>not</u> taking the action.

There are concerns about *coding systems* in health care. It was said that financial ties sometimes distort data –that we base data collection on coding and often what is coded is what pays the most, and this often compromises data accuracy. There is concern that new definitions for coding race and ethnicity will result in more inconsistencies in resultant data. Our coding system does not provide adequate data on alternative medicine.

The following were identified gaps in current data:

Many Navajos receive care in private hospitals, and in the community; and there is a

need for data beyond that obtained from the Indian Health Service if we are to have a complete picture of Native American health.

And we need to know more about *potential eligibility and need for services* –how do we know when we've "signed up" all the "eligibles" for services? For example, how many people will be eligible for Medicaid in our county, or how many seniors don't have money for medication?   This information is necessary for determining how to help people through the pharmaceutical assistance program, for example.

There is a *need for data on undocumented residents and on the traditionally underserved*. Currently, we are unable to adequately measure their needs. And we need to know more about rural logistical obstacles to accessing care.

There is a need for *geocoding*, but there is a question about what is used to do the coding.

Data on *children with chronic disability*, as well as basic demographic data on the special needs population in general.

More information is needed about *dental status*; the underserved population does not have adequate access to dental care, and data are needed to support grant proposals to improve access.

Needs for Improving Access to Data

Explanations of the importance of data both in the collection phase and in using the results is necessary for data to be of maximum use.

Many Native Americans–and others– *do not have access to computers or to the Internet*, so data must be available in paper (as well as electronic) form. There is a need to know more about households in the community with and without telephones.

There is a need to *present data in language that is more easily understood.* Many understand numbers, but not rates. Even translating results into other languages does not always help–an example was given of a very "academic" translation of Spanish that was not understood by the Spanish-speaking public at large.

It was suggested that *results be presented into categories* of "observed" and "expected," instead of simply reporting the number of people with a condition, we should specify if that is higher or lower than what is expected in the general population.

Data Needs- National

A *context about family and community* is needed when we release data–so that it can be translated into opportunities for local intervention.

It was suggested that when NCHS releases its data, that it sponsor *community-based workshops* to develop approaches based on the numbers that are released–on how to

apply the data for practical use for local areas.

Information should be shared about community processes and what communities are learning. One suggestion was for government agencies to have websites outlining, in easy-to-understand language "what works."

While national data may not be sufficient for *tracking effectiveness of interventions*, it may be good for choosing areas for intervention.

It is important for there to be *more agency collaboration in reporting systems.* Different parts of CDC require grantees to collect data in their own particular ways if they want to receive funds. Some CDC researchers have their "little proprietary surveys" and want their own way, coming across as "not only herding cats but herding cats with attitude!" HRSA and CDC researchers don't talk to each other about data from each other's agencies. It would be valuable to be able to link Census data with health care data. There is concern, though, about confidentiality issues that result from such efforts.

Data Needs- State and Local

Local area data is needed–on the county level and below.

Context variables in a community need to be considered.

The private sector may be doing a better job of looking at community level data, and this creates *opportunities for collaboration* between the public and private sector.

Compromises may be required to produce more local area data (in the way of changes in national surveys).

The suggestion was made to take large population-based surveys and *develop formulas to apply results to smaller areas*, and to develop profiles of those smaller areas. These formulas could be tested on small samples on the local level to confirm their accuracy.

While even "rough" estimation is better than "nothing at all," it is still important to have at least a small–even if imperfect– *sample of local data to go with state and national estimates*, for the data to be accepted.

The acceptability of *modeling* for local areas depends on what it is that is being predicted, ie. how the data will be used. For example, with modeling, National Health and Nutrition Examination Survey data can be safely used to predict county-level diabetes prevalence. However, such modeling would be more difficult for measuring substance abuse on the local level, since there are more local qualitative factors at play.

2. **Identify 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).**

    Technology provides opportunities to meet data needs, but also introduces concerns.

For example, the Internet greatly opens up access to data, but this includes access to users who do not know how to correctly interpret the information.

The Internet is seen as a new tool for *collecting* data, but there are also strong negatives to using it for data collection–it is too easy to assume an identity, and too difficult to verify.

Internet access is still far from universal, so we should not become too dependent on the web for information dissemination.

3. **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?**

The following were identified as the highest priority needs in building the health statistics system of the future:

capture the contribution of *complementary medicine*;

find ways to *link multiple data sets* while protecting privacy;

develop models for generating local level data;

fully utilize data collected by HMOs and government;

develop technical guides for coordinating databases, in the form of practical "how to"s;

make information in general, *more consumer and policy-maker friendly*;

collaboration between Federal health agencies and those who are not <u>health</u> agencies (ie. to look at motor vehicle injuries and deaths from transportation and health data);

change research and evaluation methods –to stop thinking in a "linear way," and instead to conduct "community process" evaluations. (For this to happen, the Federal grants process must change.); and

count some "positives," and present a picture of good health, not solely illness and disease.

Topic Area 3: Roles and Responsibilities for Providing Information and Statistics
4. **Identify the most important roles for the public sector in meeting needs for health information and statistics.**
5. **Identify the most important roles for the private sector in meeting needs for health information and statistics.**
6. **Identify the most constructive steps that could be taken by the Federal government in meeting needs for health information and statistics.**
7. **Identify the most constructive steps that could be taken by State and local governments in meeting needs for health information and statistics.**

The public and private sectors have the responsibility to *develop compatible systems* and to collaborate more on health information.

An important role for Federal and State government is to provide *technical assistance,* as well as to develop hands-on tools, with community applications, and "train the trainer" by "deputizing" selected individuals in the community to lead health promotion and health education efforts.

It is the responsibility of NCHS and other data collectors to provide *information about the impact of health studies* and not just present large tables of numbers.

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

Several groups were identified, including:

technology experts;

members of the community not involved in public health;

medical reporters;

policy makers, including legislators and school board members; physicians;

community activists and social service providers;

State government officials from departments other than Health, such as Labor and Environment;

professional associations at the State level;

"Revisioning New Mexico;"

foundations;

State licensing regulatory boards; and

providers of alternative medicine.