21st Century Health Statistics Vision Process

New Orleans Meeting Summary

A. Introduction and Background

Below is a summary of a discussion session held in New Orleans, Louisiana on March 22, 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?**

Child & Adolescent Health

> While there is a decline in infant and childhood mortality, there is an increase in morbidity–very low birth weights lead to greater numbers of children with special health care needs.
>
> Longitudinal studies are needed to track these children after they've "passed through" particular intervention programs.
>
> Disparities continue in infant mortality.
>
> Health behaviors and lifestyles that affect health continue to be important, including diet, smoking (especially among adolescents), alcohol, firearms, sexual activity and teen pregnancy.

Other

Anxiety and depression, and their relationship to chronic and infectious disease, are becoming more important.

Environmentally related morbidity and mortality, and the lack of environmental controls (for example, on lead), are concerns.

It is known that economic disparities affect health outcomes, but the reasons for disparities are not known , and thus they cannot be fully addressed.

For all of the trends and health issues discussed, there is the requirement to understand the "eco-epidemiology"– everything "from genetics to culture."

Prevalence of the following conditions are increasing:

obesity in adults and children. Childhood obesity is resulting in more Type II diabetes, though we don't have adequate reporting mechanisms for measuring the problem;

intentional and unintentional injuries;

chronic diseases such as asthma;

Hepatitis C;

HIV/AIDS.

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?**

Health Care Delivery System

The length-of-stay in hospitals is decreasing.

The uninsured population is "huge," and there is much concern about access to care.

There is a "progression" of illness among those who don't get access to care in the early stages of illness; by the time they do get care, problems multiply and are more severe.

Telephone surveys don't adequately measure the problem, because many in need are without phones (or without paid-up phone bills).

Providers in many rural areas do not exist, and people must travel far for care.

The total number of providers is known, but not where they are located, so there is not good information about shortage areas.

Medicaid reimbursement is low in Louisiana.

Medication coverage is very limited, and data are needed to help legislators understand

that long-term costs of illnesses outweigh the short-term savings from not covering medication.

Employer-based coverage is decreasing, and the limits are increasing for those who are covered (particularly for preventive care, such as pap smears).

The penetration of managed care in Louisiana is very low. There is a trend toward increased collaboration between the public and private sectors, to develop ways to combine resources and manage care.

There is a resurgence of community organizing, with the formation of local interest groups such as the Lafayette Health Consortium.

Services are becoming more integrated. For example, STD clinics now screen for other diseases as well.

Access to care over the Internet is increasing, especially among the young. But access to information is growing faster than changes in delivery of services–so we can monitor more but cannot do much about some of what we learn.

Alternative Medicine

Alternative medicine is increasing, as well as more medical self-care.

Traditional folk healers, particularly among Native Americans, are used. Physician group practices are very uncommon, which means that "a lot of individual convincing" is needed for interventions such as placing prevention posters in doctor's offices.

Other

Cultural and linguistic competence of services is increasing.

Clinical guidelines are evolving, and there is more information about medical errors and more data from which to identify best practices.

Patient non-compliance is a problem, but don't have adequate information to measure the extent of it.

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).**

With the aging of the population, there is increased attention to long-term care and increased need for data on the older population.

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:

To first make existing data accessible and useful for making an impact on health outcomes, rather than create new databases;

Better "mining" and use of information from administrative records, and from business transactions–from pharmacies, from health insurance records, and from nurse practitioner triage telephone information systems;

"Tool kits" for state and local governments, consisting of such things as sample surveys and questionnaires, "best practices," and technical assistance, including how to create a "community scorecard;"

A "data clearinghouse" to help certify the quality of existing data, what to use it for, what not to use it for, and how to use it;

Models to look at how to measure health changes; we have good models for health financing, but not for health outcomes;

Accessibility to data must to be balanced with confidentiality concerns;

Information about vital events, about incidence of reportable disease, about health care services, and about risk of injury and disease;

The etiology of disease, and how particular physical environments affect health;

Data requirements must be made in such a way that they can be fulfilled without detracting from the main focus of providing patient care;

Timely, accessible, and meaningful data; data should be displayed by local area maps and in other ways that make it easy to understand. While many have computers, most areas of the state are still without computers for collecting and disseminating data.

Data Needs- National

Standardized definitions are needed, in order to reach consensus on what must be done to address health problems.

Standards are needed to support electronic data collection–and to make it easier to exchange information and link data for multiple sources.

National recommendations for data collection are useful in setting state data requirements; it is more likely that the state will require information on birth and death certificates, for example, if the Federal government recommends it.

Federal data recommendations in related areas–such as crime, education and transportation–would also encourage collection on the local level.

Data Needs- State/Local

Adequate training must be provided for those entering data on birth and death certificates and other records, to ensure quality and accuracy.

Better tracking systems are needed in Louisiana to measure the extent of health problems.

Recent legislation will finally allow some data collection from private providers, but there are currently no systems to obtain hospital discharge data or track birth defects.

In Louisiana, there are obstacles to linking health databases, such as to Medicaid records.

Linking to other sources of data is needed in order to measure how social, economic, and educational factors influence health outcomes. However, where such data are available, there are limits it its usefulness–for example, the Education Department knows how many children are in special education programs, but cannot break this down by specific type of educational problem.

Data must be provided at a level that is "actionable" for local communities.

Data must be made "real" to people at the local level– to make it owned by those who make decisions– both individually and at the community level. This requires knowing what the community wants to measure.

Geocoding of data is needed for small area analysis; even county-level information is not necessarily adequate.

There must be enough information to know that specific interventions will meet local needs. This means that when looking at diet and health for example, taking into account such things as availability of "fast-food" in particular neighborhoods, and differences in the quality of produce among local grocery stores.

Population-based local surveys are needed.

Louisiana WIC programs provides information about children and overweight, but the WIC population is a " biased sample;" factors other than income account for nutrition, and population surveys would help identify them.

2. **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 considered priorities:

using the information we already have–to help the existing leadership to know what data are available, to present it in useful formats, and to provide guidance on how to use it. This includes developing models on the effects of potential policy changes;

modeling health outcomes, as we have models for health financing and delivery;

translating statistics into information that is "real" at the neighborhood and community level;

seeking "buy in" from the community on further data collection–if people see the value of a health measure, they will help design the collection strategy and thus "own" it; and

balancing data accessibility with confidentiality concerns.

D. Roles and Responsibilities for Providing Information and Statistics

1. Identify the most important roles for the public and private sectors in meeting needs for health information and statistics.

2. Identify the most constructive steps that could be taken by the Federal, State, and local governments in meeting needs for health information and statistics.

Federal, state, and private sector resources are needed at the local level; funds are needed for communities to recruit and hire epidemiologists who not only study diseases but who also help locals identify what is needed to improve health.

The public and private sectors have a responsibility to communicate and collaborate across all levels. This may be done through "regional data liaisons" representing all sectors.

Federal

The Federal Government should:

function as a data clearinghouse–explaining sources of data and providing its "stamp of approval" on data collected;

give communities an understanding of the importance of data and how data can impact on their health (which will in turn generate in-kind, or greater, contributions on their part); address needs for standardization and for confidentiality protections; and

provide a "tool kit" for interpreting data and identifying "best practices" for "translating data into action" at the state and local level–ensuring that program decisions are evidence-based.

These functions are seen by many as more important and appropriate for the Federal government than that of data collector.

State

State governments should collaborate with the local level in much the same way the Federal government should work with states.

Private Sector

The private sector has a role in helping to develop models to measure health outcomes.

4. **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.**

consumers;

community-based organizations;

State agencies other than the Department of Health (ie. education, transportation, economics);

employers and other benefit-group sponsors;

trade associations;

front-line data collectors such as nurses;

researchers;

legislators;

the Joint Healthcare Information Technology Alliance (JHITA), which includes groups such as the American Medical Informatics Association;

geographers;

web page designers and software developers;

“knowledge organizers” who study how to best present information;

private consulting firms; and

medical reporters and scientific journalists.