

NAHDO *news*

The Newsletter of the National Association of Health Data Organizations

SUMMER 1999

FROM THE EXECUTIVE DIRECTOR

NAHDO in Transition: Physical, Organizational and Strategic Changes Continue

What is NAHDO? How can NAHDO be of value to its members? Is NAHDO living up to its potential? Given the major changes that the organization has gone through this past year - in leadership, location, and strategic objectives - it seems fitting for us to ask these questions. While these changes created temporary operational, logistical, and communication problems, in many respects they provide NAHDO an opportunity to redefine itself, establish new priorities, and even venture into unfamiliar territory, without losing sight of its mission.

My vision of NAHDO has been shaped by eight years experience as a State Health Data Agency director and NAHDO Board member. In these roles I came to recognize the value of NAHDO as provider of a forum and network through which members strengthen each other by sharing expertise and information about each other, and collectively shape and represent their views on shared issues. NAHDO provides the opportunity for an otherwise splintered group of organizations to create a market for tools and applications to promote timely and scientifically sound collection, analysis, and dissemination of accurate health data. This will continue to be an important role for the organization. In keeping with this role, NAHDO just completed updating state health data agency profiles, supported by the Agency for Health Care Policy and Research (AHCPR), and is working to be the foremost expert in statewide health data encounter collection activities.

NAHDO is positioning to better serve as a platform or conduit for transferring expertise and knowledge through the following initiatives:

Connectivity: To survive in an economy characterized by rapid advances in information technology, NAHDO must enhance the exchange of health information and knowledge between members and partners. The NAHDO and NHIRC sites are being revised. NAHDO has secured its own server and is linked into state-of-the-art connections through the University of Utah's computing centers. The additional capacity will support repositories of information and connectivity at a lower cost than before.

Interactivity: NAHDO's new sites are being developed to promote interactivity between its members and other professionals. A Chat Room will soon be functioning. Listserves have been activated focusing on two topics: Administrative Simplification and State-Sponsored Health Surveys. Other topics can be started, based on interest and willingness from a member to serve as moderator.

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Message From The Chair

It has been a significant year for the NAHDO: staff changes, office relocation, and the implementation of an aggressive strategic plan to begin to fulfill a vision for the future. Changes, while unavoidable, do not always happen as planned and one change, in particular for NAHDO, is significant.

NAHDO bids farewell to Barbara Kurtzig who has retired after nine years of service to NAHDO and its members. Barbara did so much for NAHDO, and the Board is especially grateful to her for keeping the organization running during the recent leadership change and the development of a new strategic plan. Many of the things Barbara did were done behind the scenes—things that, if done right, were barely noticed by the members. She will be missed.

With Barbara's leaving, NAHDO evaluated the options for office structure. For reasons of efficiency and cost-effectiveness, NAHDO's administrative functions were moved to Utah in the Research Park location at the University of Utah. The organizational functions and presence in the greater DC area are still important to NAHDO, and the Board is reviewing the most cost-effective options.

It has been a pleasure to serve NAHDO as Board Chair these past two years, and I encourage existing and future members to become active in shaping this organization. I am excited about the future and believe that NAHDO and its members are up to the challenges ahead. NAHDO's strength is its diverse membership who are each leaders in their own right, but when brought together through the NAHDO network, their ability to formulate and act on creative solutions to common problems is much greater.

I hope you can join us at our Regional Meeting in Park City, Utah (September 26-28, 1999) and at our 14th Annual Meeting in Pittsburgh, Pennsylvania (January 16-18, 2000).

Louis Freedman, Chair
NAHDO Board of Directors

NAHDO's Vision for Public Health Information Systems

Highlights of Presentation by Denise Love to the Health and Human Services data council: Meeting with States on Public Health Data Needs and Issues for the 21st Century, May 10, 1999.

Six essential components of a national health information system:

1. Databases as the physical foundation.
 - Improved statewide morbidity systems as the building blocks for measurement.
 - Establishment of uniform outpatient encounter systems.
 - Standardization of critical fields.
2. Indicators and reports that reflect the purpose of the data.
 - Current report models and indicators are based on market needs of the 1990s.
 - Valid indicators that reflect the market conditions and practice patterns that emerge in the 2000s.
 - Standard indicators derived from linked morbidity and vital records data for child health, injury, maternal/women's health, and racial/ethnic indicators.
3. Linkages between similar databases nationwide.
 - AHCPR's Healthcare Cost and Utilization Project (HCUP) is a model for state-to-state and state-to-federal collaboration. HCUP is establishing a set of standardized indicators and data management procedures for integrating morbidity data across states.
 - Federal-state partnerships will expand to build and improve morbidity data systems.
 - New models of national data systems development using evolving technologies.
4. Linkage with relevant information sources.
 - Individual researchers and public health departments are linking birth, death, or Medicaid data with hospital data. Very few perform these linkages systematically.
 - Systematic linkage between important health data sets with standard linkage protocols and new indicators derived from linked data.
5. Market relevance and economic value of the data.
 - Public health will rely on partnerships with industry to collect data and be accountable for maximizing the use of the data.
 - Scientific validation of measures and models of comparative reports will promote standardization and help states balance the tensions around the public reporting of provider reports.
6. Policy relevance and political value of health information.
 - Integration of morbidity data into the public health measurement systems will add value to the data by improving the sensitivity and relevance of information about children's health and vulnerable populations.
 - Models reports for communicating information to policy makers.

Opportunities for Federal Collaboration

1. Integration
 - HIPAA
 - The Public Health Consortium is a model for public health collaboration working toward common goals.
 - Pilot projects in states to document the steps necessary to convert public health data into standard formats to achieve uniformity in health information systems.
 - Integrate federal data requirements and systems at the federal level.
 - Expand HCUP to include additional states and encounter data sets, using new models for data transfer and reporting.
 - Design of model data sharing agreements with uniform language for data use/sharing across states.
2. Indicators
 - Growing demand for market and consumer information.
 - Establishment of a national forum for validating and testing indicators, and report formats for comparative reporting will enhance the value of the information to diverse audiences.
 - Coordination of multi-specialty research and development to refine existing indicators and develop new ones that reflect current and future market conditions and practice patterns that will emerge in the 2000s.
 - Development of indicators from linked morbidity and vital records data for child health, injury, maternal, women's health, and racial/ethnic health measurement.
3. Internet
 - Taking advantage of evolving technologies will promote partnerships, data integration, and improve the timeliness and value of the data.
 - Avoid federal promotion of a single, centralized system or approach to health information systems development.

Welcome New Members:
Cardinal Health Systems
HealthInsight of Utah/Nevada

Enhanced Access to National and State Hospitalization Data Sets

As part of the AHCPR's overall effort to facilitate public use of Agency databases, 1999 inaugurates new efforts to enhance access to two databases on hospital stays. Both databases are part of the Healthcare Cost and Utilization Project (HCUP), which is a family of administrative, longitudinal databases and related software that are developed and maintained by AHCPR in partnership with states and private data organizations.

HCUP data are used for research on hospital utilization, access, charges, quality and outcomes. The data are used to describe patterns of care for uncommon as well as common diseases, analyze hospital procedures, including those that are performed infrequently, and study the care of population sub-groups such as minorities, children, women, senior citizens, and the uninsured. Researchers and policy-makers use HCUP data to identify, track, analyze and compare trends at the national, regional and state levels.

State Inpatient Databases (SID)

The SID is a collection of individual data sets from 19 participating states, each of which contains the universe of that state's hospital discharge abstracts. The data have been translated into a uniform format to facilitate cross-state comparisons. The SID represent more than half of all U.S. hospital discharges, and states' participation is growing.

Beginning this summer, distribution of 1995 and 1996 SID will be centralized for *some* of the participating states. Check the HCUP webpage (www.ahcpr.gov) for details. The Agency will continue working with the remaining states, aiming to provide centralized access for all of the 19 – soon to be 22 – SID.

National Inpatient Sample (NIS)

The NIS is a stratified probability sample of hospitals drawn from

the SID. The NIS is designed to approximate a 20 percent sample of US community hospitals, including roughly 6.5 million discharges from about 900 hospitals. NIS is the largest all-payer inpatient database in the U.S., and data are now available from 1988 to 1996.

In addition to purchasing the NIS database, an option that has been in place for the last five years, selected 1996 NIS data are now available in an interactive format on HCUPnet, which can be accessed via www.ahcpr.gov. HCUPnet accommodates browsers' real-time queries of the NIS database, providing information on number of discharges, length of stay, charges, and in-hospital mortality for diagnoses and procedures by selected patient and

The NIS can be linked with databases containing county-level information, such as the Bureau of Health Professions Area Resource File B, a database of the U.S. Health Resources and Services Administration. It can also be linked with descriptive hospital data from the American Hospital Association's Annual Survey of Hospitals.

The data set can be run on desktop computers and comes in ASCII format for ease of use with numerous off-the-shelf software products, including SAS and SPSS. NIS also includes weights for producing national and regional estimates and comes with full documentation in Adobe Acrobat. SAS and SPSS users are provided programs for converting ASCII files. The NIS Release 5 for 1996 is available on CD-ROM with accompanying documentation for \$160 from the National Technical Information Service, Port Royal Road, Springfield, Va., 22161 (1-800-553-6847 or 703-605-6000). The product number is PB99-500480. The cost may be higher for customers outside the United States, Canada and Mexico. Data from earlier NIS releases (1988 - 1995) are also available from NTIS. For more information, see HCUP Nationwide Inpatient Sample (NIS) on AHCPR's web site: <http://www.ahcpr.gov>.

NAHDO IN TRANSITION *continued from page 1*

Products and Services: NAHDO's strength has always been its members and network of professionals. NAHDO will work to enhance these intangibles, and coalesce these relationships into tangible products: data bases, publications, Internet tools, and standards for data sharing and comparing. NAHDO will be challenged to provide these services and products faster and to a broader audience.

With these initiatives, NAHDO has added a new dimension to its function - providing products and services to leverage the visibility of the organization, its members, and the collective expertise it

represents. Accomplishing these will require support from industry and federal sources and a commitment of time and expertise from the membership and may include the following: publication of white papers, interactive discussion groups, specialized meetings, and development of industry databases and benchmarks.

Capitalizing on its historic role of fostering networking and connections between organizations, NAHDO has the potential to go beyond meeting its members' needs to leveraging its role in establishing a nationwide health information system for improving health and health quality. I am excited by this opportunity.

New York State

Discharge Data System

The New York State discharge data system, referred to as the Statewide Planning and Research Cooperative System (SPARCS), was established in the late 1970's. The original architects of the system pioneered the concept of a standards-based data collection system. The financial information was reported on the first uniform billing form (UBF-1) in the country. The clinical data adopted many of the NCVHS recommendations contained in the Uniform Hospital Discharge Data Set (UHDDS), which was a precursor of the current Core data elements.

Born from that tradition, the current SPARCS system seeks standards-based solutions to the evolutionary enhancements resulting from ongoing changes in the nation's health delivery systems. New York State providers have strongly suggested that the quality of data reported to SPARCS correlates directly to alignment with hospital financial systems. For this reason, planning to migrate SPARCS to the HIPAA mandated standards is in full progress. Step one occurred in 1994, when New York State, including SPARCS, adopted the UB-92 institutional billing form. That replaced the established NYS proprietary UBF-1. Step two has been an ongoing effort to educate the user community about the advantages of a standards-based system. The improvements in data quality were balanced against the need for state-specific information.

With this groundwork as the basis for action, an initiative was started to identify data elements with a proven need that were not supported by the expected HIPAA mandated transactions. Once a data element has been identified, a variety of strategies have been employed to facilitate the planned migration to nationally supported standards for the SPARCS system.

Strategies:

- Educate users on the national standard to determine if an equivalent function could be served by data elements already defined in the standard. An example of this was the collection of Alternate Level of Care data (type, date, & number of days). This required a process change for SPARCS while providing the user community an improvement in the quality of the data, which is now being reported using nationally supported data elements.
- Require users to justify the data collection costs compared to the usage for that particular data element. Elements that could not be justified in this manner would no longer be required. A high profile example of this was the Do Not Resuscitate indicator, which was dropped because it was not being used.
- Work with national Standards Development Organizations (SDOs) to get needed state data elements defined on the appropriate standard. An example of this is the addition of the Onset of Secondary Diagnosis indicator on the ANSI ASC X12N 837 transaction set standard.

At the moment there are only a few data elements required by SPARCS that are not currently supported by the proposed HIPAA transaction standards. Based on the progress made to date, we expect the New York State discharge data will be reported using the appropriate national standards when the HIPAA law is implemented in the year 2002.

Emergency Department Data Collection Presents New Challenges, Opportunities for States

Compared to hospital inpatient discharge database development, which has been the primary activity of health data organizations, development of emergency department databases is a relatively new frontier. Given the continuing shift of health care from hospital inpatient setting, it has become essential for health data organizations to collect non-inpatient data. Additionally, managed care organizations have identified emergency departments as an opportunity for cost reduction through limitation of its inappropriate use. Therefore, it is becoming imperative for health data organizations to venture into this area of data development.

There exist other sources for ED data (National Discharge Surveys, Trauma Registries). All have limitations, but population-based data is most useful for state purposes: Patterns and outcomes analyses, utilization trends, access to care by subgroups, importance to women's and children's health. For HDOs already collecting hospital inpatient data, technical issues are familiar given the similarity of data elements and definitions.

In a recently completed survey of states conducted by NAHDO as part of the Healthcare Cost and Utilization Project, by the Agency for Health Care Policy and Research, eighteen states reported

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EMERGENCY DEPARTMENT DATA *Continued from page 4*

collecting 1998 Emergency Department (ED) encounter data (see table below). Of these, ten were state data organizations with a mandate and nine were private data organizations (mostly hospital associations) collecting from hospitals on a voluntary basis. Organizations not collecting ED data cited monetary, political and legal constraints as the primary barriers.

Utah is one of the states that have successfully established an all-payer database of visits to hospital emergency departments. Starting with 1996 encounters as base year, Utah now has three years of data. The database is being maintained by the Office of Health Care Statistics (formerly Office of Health Data Analysis), in collaboration with the Bureau of Emergency Medical Services (BEMS) of the State Health Department. Submission by hospital is mandated by an administrative rule under the authority of two statutes: the Utah Emergency Medical Services Systems Act and the Utah Health Data Authority Act. Public datasets for 1996 and 1997 are now available in various formats.

Factors that contributed to the successful establishment of the database in Utah included:

- (1) Agreement with data suppliers to facilitate data submission through a single point for both inpatient and ED data
- (2) Having an established inpatient data collection and reporting simplified the otherwise rigorous and lengthy process data organizations have to go through to develop methodologies and protocols, and to obtain acceptance of stakeholders.
- (3) Close collaboration with the Bureau of Emergency Medical Services in tracking compliance, resolution of data quality issues, design of reports, and dissemination.

How can other data organizations considering collecting ED data benefit from the experiences of Utah and the rest of the eighteen organizations mentioned above? Now that some states have had experience with the collection, analysis and dissemination of emergency data, the timing may be right for a NAHDO-brokered collaboration among member organizations NAHDO's role may include any of the following:

- Coordinate the creation of a users' group or an ED database committee.
- Integrate ED data collection, analysis and dissemination issues in conference agenda.
- Compile and make available a list of experts as resources to member organizations.
- Establish means of communication, sharing of expertise, edit protocols, programs
- Review edit protocols and suggest minimal reference/edit checks.

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A query system is being developed to allow users access to the Utah E.D. data through the internet. The system is currently for internal use only but by the middle of Fall 1999, a link to the system can be found in BEMS's homepage-
<http://hlunix.hl.state.ut.us/ems>.

NAHDO NEWStats

General Overview of Statewide Data Collection Activities

Type of Data	Total States Collecting	Mandated Reporting	Voluntary Reporting
Inpatient	44	34	10
Ambulatory Surgery-Hospital Based	26	15	11
Ambulatory Surgery-Freestanding	13*	11	2*
Emergency Department-Hospital	18*	10	8*
Outpatient Hospital (non-surgery, non-emergency)	11	8	3

*may represent pilot data collection projects that are not statewide reporting systems

NAHDO's 1998 State Health Data Agency Profile

Includes either a state data organization or a private data organization for each state collecting statewide encounter data.

Seven states do not collect statewide encounter data for public use.

May include voluntary pilot data collection efforts in which full compliance to reporting is not achieved.

NAHDO's State Health Data Agency Profile, updated through a recent Inventory of State Encounter Data Availability funded by AHCPR, 1999.

Privacy Regulations Expected

Congress missed the August 21, 1999 HIPAA deadline to pass medical privacy legislation and now the responsibility to draft regulations protecting medical information held in electronic form falls to HHS. Congress will most likely continue working on legislation after lawmakers return from their August recess, but HHS staff are drafting privacy regulations in case that legislation is not passed. HHS staff are using Secretary Shalala's 1997 Statement of Recommendations for Protecting Medical Records Privacy, which is serving as the framework for the draft regulations. One of the examples of the challenges associated with this translation is the patient's right to determine who can see what portion of their medical record. Regulating the separation and tracking of all disclosures through a complete listing of individuals and organizations accessing the record is at odds with how health care is delivered today.

Another one of the challenges, according to Bill Braithwaite (a senior advisor for HHS), is correctly defining the terms and entities that operate in today's health care system (e.g. health care operations, health care clearinghouses). According to Braithwaite, how these entities are defined "affects who is

subject to coverage under the regulations and ultimately determines if medical records held by these entities will receive regulatory protection".

The regulation will be issued as a notice of proposed rulemaking with comment period in the Federal Register and may be similar to proposed rules on transactions and security standards issued in 1998. Like these other rules, the privacy rule may not include any enforcement provisions. The department may consider a global enforcement rule in 2000 to cover all of the rules issued under the administrative simplification provisions of HIPAA.

NAHDO will be tracking the development of these regulations and the emergence of federal legislation relative to privacy of medical records. At NAHDO's Regional Meeting in Park City, on September 26, 1999, states will consider drafting a proposed definition for state health data organizations, which will be posted for review and comment on the NAHDO website (www.nahdo.org) and eventually forwarded to HHS and congressional staff.

NAHDO NEWStats

Do you plan to change your format to meet HIPAA standards?

Data Type	Yes	Don't Know	No
Inpatient	25	12	2
Amb Surgery - Hospital based	18	5	1
Amb Surgery - Freestanding	10	3	0
Emergency Department	11	5	1
Outpatient Hospital (non-surgery/ED)	10	0	1
Group MD*	1	0	0
Individual	2	0	0
Managed Care	1	0	0
Medicaid	5	3	1

*MD= Physician encounter data

44 states responding to a recent Inventory of State Encounter Data Availability funded by AHCPR, 1999.

NAHDO Strengthens Internet Presence Through Partnerships

A major thrust of NAHDO for the next few years will be to continue the development of Internet sites to serve the health data community. The following projects are currently underway with the help of members and various organizations.

HCUP Quality Indicators On-Line

With funding from the Agency for Health Care Policy and Research, NAHDO has developed a query system to provide users access to HCUP QIs derived from State Inpatient Databases (SID) of HCUP participating states. To be completed October 1999, the system allows internet users to calculate QIs by selected patient and hospital factors. This system will be made available to states requesting the system. Adjustments can be made to comply with state data disclosure constraints.

Health Care Site Search Index

The Society of Actuaries has provided funding for NAHDO to enhance its website by including a module to provide users a way to search health care related internet sites. The site, now halfway through its development and expected to be activated in October, includes four search options: The first is a guided search where the

user specifies the type of information sought (organizational information, data, publications), the type of organization, or domain of interest (including broad categories of diseases). The second is a listing of all sites reviewed by NAHDO and included in its database. The third option is searching by keyword. The fourth option is a patch into selected search engines.

Enhancements to NHIRC

The NAHDO and NHIRC sites have been transferred from a commercial Internet Service Provider (ISP) to NAHDO's own repository. This transfer was necessary as NAHDO is developing interactive Internet data systems and needs storage and software capacity not readily available through most commercial ISPs. During this transfer, the NHIRC domain address was down, therefore requiring access through the NAHDO site (www.nahdo.org). Enhancements to the NAHDO web resources include the addition of a chat room function (to be activated with interactive membership resources by November 1999). We apologize for any inconvenience during the transfer of website addresses.

HCUP Quality Indicators On-Line

Health care quality initiatives rely on a source of comparable data, including benchmarks. To help meet this growing demand for quality indicators and to maximize the utility of the Healthcare Cost and Utilization Project (HCUP) national and state data, the Agency for Health Care Policy and Research (AHCPR), in partnership with the National Association of Health Data Organizations (NAHDO) is establishing an Internet query system for on-line access to HCUP Quality Indicators (HCUP Quality Indicators On-Line).

The purpose of this on-line system is to disseminate objective, comparable information about outcomes of hospital care, use of hospital procedures, and ambulatory-care-sensitive conditions.

The HCUP Quality Indicators On-Line System will provide:

- A user-friendly interface to enable custom queries of each indicator by patient demographics (age, sex, payer status) or hospital factors (ownership, location, teaching status, bedsize).
- Dynamic and non-dynamic homepages with information about HCUP, the indicators, and results of the queries.
- A flexible system accessible through the Internet that is not platform-dependent.
- Options for graphic or table output.

The statistical calculation and output of each indicator is performed by the query program, thus permitting the replication of standardized and accurate results across users and settings while automatically

suppressing small numbers at output. Central maintenance and update of this system will accommodate revisions and updates in the Quality Indicators algorithms.

The Advisory Committee for this project is the Quality Indicators Workgroup, a coalition of HCUP data suppliers and HCUP data users.

What's next?

After the implementation of this system, maintenance and updating will be conducted by NAHDO and AHCPR. This system can be expanded to other types of indicators (non-inpatient) and indicators from linked data sets.

For more information, call or email:
Denise Love, NAHDO
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WHERE IN THE WORLD IS NAHDO?

Lately, the frequently asked questions to NAHDO have revolved around ways to get in touch with us. As many of you are aware, we had been operating from two locations since November, 1998: one in Washington, DC and the other in Salt Lake City.

With the departure of Barbara Kurtzig, the NAHDO Board decided to temporarily close the Washington, DC office to allow some time for us to strategically evaluate the functioning of the organization and assess options to re-establish its Washington, DC presence.

As of September, 1999, all NAHDO communications will emanate from and must be directed to the Salt Lake City office. In addition to its physical address, NAHDO's internet address has changed as well. We apologize for any inconvenience during the transition.

Please take note of our new addresses and numbers:

Address:

391 Chipeta Way Suite G P.O. Box 58229
Salt Lake City, UT 84108 Salt Lake City, UT 84158

Phones:

(888) 747-6936 (Toll-Free) (801) 587-9118 (Denise Love)
(801) 587-9104 (Carrie Chen) (801) 587-9108 (Trent Lemperle)

Fax: (801) 587-9125

Email: Dlove@NAHDO.org
Cchen@NAHDO.org

Website: www.nahdo.org (With link to the NHIRC)

ANNOUNCEMENTS:

2000 Association for Health Services Research Annual Meeting

Research to Action: The Role of Health Services Research
June 25-27, 2000 Westin Bonaventure, Los Angeles, CA

The meeting offers over 100 sessions dealing with issues critical to access, quality, and cost of health care.

Visit our website, www.ahsr.org, to request meeting

NAHDO announces two Listserves:

Administrative Simplification Listserve - for a discussion of the latest developments under HIPAA and to help shape NAHDO's response to these developments.

Send email to subscribe:

TO: LISTS@DFPM.UTAH.EDU
SUBJECT: (anything)
SUB NAHDO-ADMINSIMP [your email address]

State-Sponsored Health Surveys Listserve - for individuals interested in state-sponsored health surveys, a forum for the exchange of tools and best practices in population-based surveys.

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NAHDO

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