3rd Annual Meeting
Public Health Data Standards Consortium
Steering Committee

Summary of Proceedings

March 20-21, 2002

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Welcome – Consortium Goals and Accomplishments

Ms. Marjorie Greenberg welcomed participants to the Third Annual Meeting of the Public Health Data Standards Consortium Steering Committee. After introductions, she expressed appreciation to the sponsors (see attached). Then the Steering Committee paused to remember Dr. John M. Eisenberg, Director of the Agency for Healthcare Research and Quality (AHRQ), who passed away on March 10, 2002.

Ms. Greenberg briefly reviewed the events of the last year, noting especially the lessons learned as a result of the September 11 attack, that information systems are currently inadequate. Clearly data standards are a critical priority – classifications systems, core data sets, identifiers, message formats, implementation guides, and privacy and security. Development of these standardsd will create a common language that will enhance data sharing, integration and comparison of data from many data sources.

A standards "momentum" has emerged with the HIPAA and the recent congressional action that is a reaffirmation of the HIPAA provisions, the development of standards by the National Committee on Vital and Health Statistics (NCVHS) on various fronts (PRMI, NHII and the 21st century health statistics reports), the National Electronic Disease Surveillance System (NEDSS), which provides key elements of the IT specifications and functions for bioterrorism grants, and the support of the American Medical Informatics Association (AMIA) 2001 Spring Congress for public health informatics and standards. The National Center for Health Statistics (NCHS) and the states are aggressively re-engineering vital records, and the state Medicaid agencies are embracing standards under HIPAA. Finally, the e-Health Initiative is promoting public-private partnerships using national non-proprietary standards.

Ms. Greenberg commented that the Consortium, a group of 35 organizations, is committed to the promotion of data standards for public health and health services research and is part of this momentum. Accomplishments to date include endorsement of the Consortium's Education Strategy, followed by a meeting in July 2001 of key partners, who arrived at a consensus that the Consortium's mission is multi-layered and multi-phased and goes beyond the basic implementation of HIPAA. That meeting also provided guidance to the workgroups that were established at the Second Annual Steering Committee meeting, all of which subsequently have held conference calls and agreed on mission and charge. The current workgroups are: Business Development and Marketing, E-Codes, Health Care Services Data Reporting Guide, Overcoming Barriers, Web-Based Resource Center, and a Planning workgroup.

The Consortium has continued to promote essential data content, including E-Codes, the capture of newborn birth weight (which was at risk of elimination in the DSMO process), and collection of race and ethnicity data.

Finally, the Consortium has continued to represent public health and research at the NUBC and NUCC, with standards development organizations (X12 and HL-7), and in the DSMO process.

Ms. Greenberg recognized with appreciation the workgroup chairs (who present updates below), and the core NCHS staff who support the Consortium – Suzie Burke-Bebee, Hetty Khan, Michelle Williamson and Donna Pickett. She also expressed appreciation to Consortium members who have participated in the workgroups.

Concerning the future, Ms. Greenberg mentioned challenges and potential projects – strengthening partnerships, adding a synergy to other data standards activities, increasing the contribution and participation of Consortium members, identifying resources for Consortium projects and spreading the standards message through education. She outlined specific opportunities for the next year – support for workgroup projects and leveraging the Homeland Security and other funding related to public health to include a data standards element (especially and specifically working with states, NEDSS and developing emergency department infrastructure).

Workgroup Updates

E-Codes

Ms. Greenberg recognized the contribution of workgroup co-chair Andye Zach, who is retiring from the Office of Statewide Health Planning & Development (OSHPD). Dr. Arturo Coto, co-chair, reported that the initial charge of the workgroup was to develop a rationale for the expansion of E-Codes, later amending the charge to include an evaluation of E-Code collection nationally and to recommend improvements to any E-Code standards developed in the future. Through a series of conference calls, the workgroup developed a presentation to X12N, which accepted the Health Care Service Reporting Guide as a standard implementation guide and incorporated the multiple E-Codes into that guide. The workgroup agreed that its recommendations must be compatible with ICD-10. The workgroup will request 6 positions for E-Codes, which may be used for multiple causes or to more completely detail a single injury. Currently the ICD-10 requires mechanism of injury, location and activity of victim when injured.

Dr. Coto mentioned a workgroup recommendation, that the business case be revised to address any concerns of the NUBC – payments, billing, support of carriers to provide data.

During discussion, there was a recommendation to encourage law enforcement to contribute to data collection and to coordinate E-Codes in situations involving disaster, terrorism and crime. There was a comment that the needs of many agencies (e.g., EPA, FDA, CDC, law enforcement, etc.) underlines the importance of a standard so that data exchange is facilitated. There was a suggestion to link with Partners for Community Safety (on the AHA web site), a group that is concerned with acute and emergency care in the public health sector. It was also noted that the availability of a number of fields for

E-Codes should be examined, especially because the electronic reporting systems can accommodate a greater number of fields than the paper-based system.

Business Development and Marketing

Dr. Walter Suarez, co-chair, commented that the workgroup, established in July 2001, has addressed development of a business plan with a marketing component. Objectives were identified – funding requirements for the projects of the Consortium and identification of funding sources and potential partners to provide that funding. The workgroup also looked at identifying partners who could participate in the projects, as well as marketing specific projects to appropriate groups – researchers, public health constituents and others. The workgroup developed its own charter, which includes project classification (with selection criteria and a review process for project proposals) and the drafting of a preliminary business plan. The workgroup has already begun working with other workgroups to identify business development needs.

Mr. Elliot Stone, co-chair, closed the workgroup update by expressing appreciation to staff and the workgroup volunteers.

Overcoming Barriers/ Strategic Planning

Mr. Delton Atkinson, chair, reported that the workgroup's focus has been on strategies for overcoming barriers to the migration of public health data to a national standard, in part by using HIPAA data standards more effectively and working with the public sector at the state and local levels. A charter was developed that began with identification of main barriers – lack of a clear mandate for public health and health services research to adopt standards, a concomitant lack of national leadership and funding, and a paucity of knowledge at the state and local levels of where to begin, with accompanying fragmentation of efforts. There is a clear need for change in the many state and local programs and systems, which is met by staff and organizational resistance to that change and a general lack of coordination in trying to bridge multiple data standards and establish integration processes.

The workgroup agreed that attacking all of barriers at one time would be ineffective, so it prioritized the challenges (in the order above) and developed general guidelines for addressing them. As a practical matter, Mr. Atkinson observed that the workgroup agreed that an appropriate first step would be to focus on emergency room data collection and storage.

National Electronic Disease Surveillance System (NEDSS)

Dr. Claire Broome explained the importance of deriving useful functions from many of the more abstract aspects of the existing data standards discussion, noting that NEDSS can deliver practical results using data standards. NEDSS is a broad-based initiative that relies on national data and information systems architecture standards to help develop

effective and interoperable surveillance systems at the state and local level. Models, logical and physical, are now available on the NEDSS web site, both derived from on the HL-7 reference information model. The system architecture is also on the web site. It is based on an integrated data repository that can handle data entered over the web or via HL7 messages from the clinical sector. NEDSS initially worked with large multi-jurisdictional clinical laboratories to implement the HL7 messaging function. There is also coordination with the e-Health Initiative group to include commercial partners, looking beyond clinical lab data as a resource for electronic symptomatic surveillance.

Security standards (within the parameters of HIPAA) assure partners that data is protected. Finally, although NEDSS main mission is to help track infectious disease, the architecture would be compatible with other surveillance requirements.

Currently every state, six cities and one territory are receiving funding to support a NEDSS effort. The majority (43 states) are using the initial funding for assessment and planning for a NEDSS-compatible surveillance system. In September 2001, 35 states and one city were funded to implement systems (some integrated NEDSS standards into existing systems, and some deployed the NEDSS Base System). The Base System allowed states to deploy a system that includes core demographics, a national notifiable disease module, a person-based integrated data repository and HL-7 messaging, standard messaging and a database model.

In January 2002, CDC and HRSA provided major funding for state and local public health preparedness capacity, which included and gave a potential boost to surveillance and IT capacity. IT is a critical element of most systems. The guidance to grantees from CDC and HRSA requires that IT investments conform to the IT specifications and functions included as an appendix. The IT function and specifications include automated and manual data entry and exchange for event detection, contact information, access to and analysis of clinical data related to event detection (including specimen and lab result information), and a public health alert/information dissemination function. NEDSS standards are incorporated into these broader specifications and functions.

The states have clearly indicated a need for interoperable systems, which NEDSS offers. Its architecture is not specific to just infectious disease, and it uses actual and de facto national standards as a foundation that state and local systems can build on.

Dr. Broome stated that working groups at the Institute of Medicine's (IOM) National Quality Forum agreed that bioterrorism preparedness, based on standard vocabularies and messaging capacity, could be a driver in developing standards for generalized clinical systems.

NEDSS is encouraged by the participation of state and local health departments and other groups, catalyzed by the e-Health Initiative, in moving towards national standards and away from fragmented, proprietary systems. Finally, NEDSS has interacted with the Department of Health and Human Services (DHHS) Data Council and the National Committee on Vital and Health Statistics (NCVHS), and there has been support for the

notion that NEDSS can be compatible with the national health information infrastructure (NHII) and can support public health reporting requirements.

During discussion, concerning interagency cooperation in managing data, Dr. Broome stated that the need for such cooperation is a clear statement of the need for data standards. The existing standards organizations should be the foundation on which those data standards are built, but there must be a strong effort to insure the public health requirements are included in the process. Public health users must actively participate in the process and that involves providing them with information/education on what is currently available and is possible and needed.

Dr. Barry Gordon, California Cancer Registry, expressed concern that system builders are rushing to XML without any standards to guide them. He urged responsible and knowledgeable agencies to begin to take public positions that would help guide the development of XML.

Mr. Elliot Stone noted that there is local concern about how to obtain and implement security technologies, many of which are exceptionally costly. He said that states need guidance in how to identify products that are effective and less costly.

Asked about interfacing with data systems that currently exist that are not specifically public health systems, Dr. Broome suggested that NEDSS changes the approach for surveillance from "disease specific" to a flexible, data source-based system that allows data source efficient collection and distribution of data to a single point at a health department, and then to a variety of users. Therefore, the business process is as important as the data process.

There was a suggestion that the Consortium should examine how to more effectively influence the standards setting organizations (like HL-7) when so few members actually belong to those organizations and are not involved in the pragmatic aspects of the process. Finally, there was an observation that the Homeland Security funding, although substantial, would not be sufficient to "solve" the current needs for better data access, therefore, the Consortium should be initially focused on achievable relatively short-term programs and projects.

Workgroup Activities

Health Care Services Data Reporting Guide

Ms. Denise Love introduced the discussion of the Guide, noting that 44 states currently collect discharge data for surveillance, quality control and other non-billing reasons. In doing that, most states define their core data elements in conformance with national data standards. A 1998 NAHDO survey identified priority data elements that were helpful in establishing the Consortium workgroups and were used to create the Guide. If the Guide is effective, data collection should be extended to the outpatient population and ultimately the private sector (physician's office).

Mr. Robert Davis stated that a year ago the Health Care Services Data Reporting Guide was just a concept that has now become a working document, open to improvement, but currently available. He explained that the guiding principle in developing the Reporting Guide was "to follow the data source", which early on turned out to be the X12 standard. The Reporting Guide accepted the 837 standard maximum data set, which comprises the total data set, with internal and external data elements and codes. Eventually other data sources will be considered for future amendments to the guide. Through the work on the Reporting Guide, data standards groups, like X12, have come to accept the Consortium as an integral part of the standards development process. Because data standards are complex, the Consortium will enhance the understanding of the standards and their development process through a Web-based Resource Center.

In developing the Reporting Guide, comments came from not only the workgroup members, but also from a broad audience that included data standards groups (mainly billing data) and public health data standards interests.

There are aspects of the Reporting Guide that are particularly important to the public health data community, such as the adjustment of element descriptors so that the traditionally thought of "billing data" becomes useful and known as "service provider data"; continual adjustments to the Reporting Guide as a result of proactive industry outreach involving more minds in the process; a semantic process to ensure that terms are more understandable and appropriate to public health; and an effort to effect a parallel approach to object descriptors that enable transition to XML. Mr. Davis presented a time line that projected publication of the Reporting Guide by X12N by the end of 2002.

Mr. Davis also described the New York State experience that began with widely supported legislation to enable collection of emergency department (ED) data, which was, in turn, supported by New York's largest hospital association (provided the data was handled in accordance with HIPAA). A preliminary test of data was recently submitted by a single hospital to the SPARCS discharge data system and was found to be successful because the data was current, complete and included the appropriate codes. This preliminary test indicates that, with the buy-in of the institutions and clinicians, useful data can be collected that will conform to the requirements of the Reporting Guide. An important consideration in this process, when applied nationally, will be the need for the public health data community to speak in a unified voice in support of implementation of the Reporting Guide.

Ms. Love with the assistance of Ms. Michelle Williamson showed the Reporting Guide and educational materials on the NAHDO web site (which will eventually be moved to the Consortium site).

Web-Based Resource Center

Tom Doremus described the workgroup's approach to developing a web-based educational resource for a wide variety of individuals and organizations, including a

program design that would encourage the sharing of ideas. The workgroup conducted a survey to determine training needs and to create a profile of the potential audience for the web-based training programs. Survey respondents were comprised of interested persons from state and local health departments (slightly less than half of all respondents) and, to a lesser extent, associations, academia, federal agencies, hospitals and clinics, not-for-profits and advocacy groups, and commercial users. In all, 165 responded to the questionnaire.

The functional description of respondents indicated that almost half were data "users" or "decision makers" who depended on data for making decisions, and about one-third were data collectors. The rest were data suppliers or a non-defined "other." About two-thirds admitted to being "somewhat" or "very" familiar with HIPAA and the basic process of standards development. Seventy-five percent stated that they had no participation in the standards setting process at the national level; sixty-three percent and fifty-eight percent had no participation at the state and local level respectively. The profile of the survey respondents demonstrated that a substantial number (and by extension, much of the public health and health research community) could benefit from an effective web-based education/training resource.

The respondents indicated that there is a process in place (or planned) for developing data standards where they work (69%), and a process for adopting those standards (also 69%). Eighty-five percent of respondents confirmed data sharing with other health care providers, both public and private organizations. It was revealed that groups were primarily interested in access to notifiable diseases data (63%), encounter data (61%), and laboratory data (48%). The survey results support a real need for collaboration and coordination of efforts across/within entities and easy access to appropriate health data standards training, which the web-based resource center could provide. Respondents relied mainly on coding standards such as ICD-9 and CPT-4, and to a lesser degree on ICD-10 and HCPCS, with nominal mention of SNOMED and NDC. The major message formats identified as in use by the responding agencies were HL-7 (21%) and X12 (8%).

Asked about data standards training, more than half (56%) of the organizations indicated that they did not provide a program, blaming scheduling obstacles (46%), lack of awareness of relevant training (45%), and lack of funding (42%). As far as type of training suggested by the respondents, a general overview of training and training focused on specific standards received about equal scores and 69% identified a combined approach as most useful. On-line self-paced tutorials were the training method of choice, although a reasonable amount of interest was expressed for a variety of other methods. Mr. Doremus noted that the remaining questions in the survey pertained to organization staffing and computer capacities. The answers indicated that most of the agencies and organizations included less than 25 health data staff (58%) and most were reasonably well-equipped technically to allow for web-based training.

In closing, Mr. Doremus discussed next steps such as a major effort to create the web site content (sure to be resource intensive), including a process for obtaining continued annotated Web-site suggestions/evaluations, asking that all in attendance suggest sites via

the Consortium listservs or e-mail directly to him at tdoremus@phf.org. During discussions, it was noted that the number of individuals employed by or associated with the Consortium member organizations was very large, and that the Consortium membership might be a good initial and natural audience for the Web-based Resource Center promotion efforts.

Comments from Sponsors

AT&T

Ms. Maureen Kitchelt, Director of Business Development, Strategic IT Accounts, expressed appreciation for the opportunity to share sponsorship of the Consortium Steering Committee meeting. She explained that AT&T had developed an approach to data management, enterprise integrated applications. The applications are supported by the extensive and well-established AT&T system, which also provides a high level of security. The AT&T approach is a proven approach to integrating major data resources from widely disparate systems, based on the existing AT&T infrastructure, innovative software, and the company's extensive experience in working with major federal, state and local clients.

Microsoft

Mr. Ron Ridderbusch, Partner Account Manager-Health and Human Services, Microsoft Government Solutions Group, discussed Microsoft's recent two-year entry into the state and local health and humans services market. He explained that his company was making a major effort to understand the business of data standards and data management as it applies to the government agencies involved in trying to provide data services. The company has already begun to offer solutions including commercial-off-the-shelf (COTS) software for HIPAA implementation. Mr. Ridderbusch noted that, as with many of the groups involved with the data standards challenge, Microsoft is committed to XML and to the delivery of systems that can communicate and make data integration more efficient and effective. He expressed that Microsoft has a major interest in developing a continuing relationship with the Consortium.

Assuring the Health of the Public in the 21st Century

Ms. Monica Ruiz discussed the Institute of Medicine's (IOM) new study on the future of public health, which was prompted by the dramatic changes in the last decade in how public health services are delivered and funded. The report is a third in a series of IOM reports and will target public health professionals and health care practitioners, as well as educators, concerned individuals and groups, and policy makers and legislators. The first IOM study was completed in 1988 with the final report titled, "The Future of Public Health"; the second study, "Healthy Communities: Future Partnerships for the Future of

Public Health" was completed in 1996. The newest IOM study hopes to improve the understanding of public health issues among those audiences, identify the knowledge that can lead to change, and develop an agenda to enable the public health community to improve population-based health. The report will also make recommendations for improving practice and health outcomes, describe how to build capacity for getting the job done, and identify strategic investments for grant-makers and funders, both public and private. The report, originally planned for completion this month, was delayed due to the September and October terrorist events of last year. The final report is expected sometime in the summer of 2002.
The IOM Committee's charge is to describe a new, more inclusive framework for assessing population-level health that can be effectively communicated to – and acted upon by – diverse communities. The Committee's methodology includes regular meetings for gathering information and deliberations related to the final report, site visits, public hearings, a major literature search, and gathering data from various local, state and federal agencies. The "drivers" that will shape the population health include environmental changes, infectious disease threats and incidents, disparities in health status and health care access, advances in biotechnology and information technology, the social/political state of mind that sets public health priorities, and the impact of globalization. The "team" that finally produces the next level and quality of care includes the private sector, health care provider systems, communities and governments.

During discussion, Ms. Ruiz stated that the IOM Committee had an excellent resource in Dr. John Lumpkin, member of the NCVHS and participant in Consortium meetings, for information related to the data standards process. Asked about linkages at The Academy between the public health committee and the committees working on quality and immunization, she added that there are members on the committee who are also on the immunization committees, and there is a close working relationship with the office in the IOM responsible for immunization studies.

From NHII to the Health Officer's Desktop

Desktop of the Future

Drs. John Lumpkin and William Yasnoff coordinated their presentations.

Dr. William Yasnoff began his presentation with an audio/visual demonstration of a health officer's desktop in the year 2010. It provided online data available for surveillance, tracking cases, health alerts from other jurisdictions, and other information enabling a health department official to function effectively in the 21st Century. Online health information resources included instant guidance in specific infectious disease threats, alerts to emerging global health situations, and access to international media reports, literature searches (e.g., MedLine) and desktop communications to both pre-set addressees and to the health care community in general to allow an inquiry about any infectious disease threat.

The National Health Information Infrastructure (NHII)

Next, Dr. John Lumpkin presented an in-depth review of the National Health Information Infrastructure (NHII). The presentation began with a description of the traditional public health discovery of a disease threat: the concentration of a disease tracked geographically with its appearance being greater than normal in rare disease events. The next step in the discovery process was portrayed as a direct public health system investigation, which revealed a probable cause: a contaminated water source or food. The final step in the process leads to corrective action and the prevention of an epidemic. This is public health response at its best.
Dr. Lumpkin noted that, in this process, the technology that most public health departments rely on is a written incident report communicated to others by mail or telephone – technology that was popular in the twenties. He also noted that since the time of Hippocrates public health services have the complex combination of environmental conditions and social and political forces. Also, public health's responsibility is spread across the entire community – the community being the governments, the physicians (the health care community), and public and private groups.

The obstacles that hinder a truly effective public health system include: the cost of the data capture and management; the inability to link data across geography through time, and between disparate systems. Finally, although knowledge exists about how to do it, there has not been an effective application of that knowledge.

Dr. Lumpkin commented that the September 11 terrorist attacks and the subsequent October anthrax events changed the rules and illuminated the importance of the public health system. Bioterrorism (BT) requires a more sophisticated approach than the traditional public health scheme. This approach requires a more rapid disclosure and an immediate ability to manage the event, which requires integrating a number of possible solutions to establish control with information technology as a critical element.

The NHII provides a vehicle for that integration. Dr. Lumpkin stressed that NHII is not to be thought of as a centralized database, but as an infrastructure that facilitates the identification and retrieval of health data from many sources. Within the NHII, data will be available from three distinct domains: the health care provider (or caregiver), the individual (or patient), and the community. The domains relate to the NHII's three health dimensions (respectively): the health care provider dimension, the personal dimension and the community dimension.

Dr. Lumpkin explained that once the components were in place there would need to be an evaluation of the system, which would result in a number of tasks needing to be implemented. The tasks would be implemented in three stages covering a two to ten year period. In the first stage (two years), the infrastructure would include DHHS leadership, the development of an implementation plan, the establishment of incentives and requirements and an accelerated process, and a commitment of resources. The second stage (five years) would concentrate on developing and expanding collaborations and the third stage would carry out the actual NHII implementation.

It is clear that leadership is required for a successful implementation of the NHII and that the leadership needs to come from the federal government. Federal leadership would coordinate the evolution of the NHII, would influence spending, security and confidentiality policies, and would promote state and local buy-in. It would guide training, consensus, standards, and international collaboration and foster a team approach of the development and implementation of the NHII.

Dr. Lumpkin expressed the opinion that the federal government must coordinate funding and oversee the development of standards. He added that perhaps the most important first step should be the automation of a medical record system for emergency departments. Finally, he said that when the federal government acted in support of these programs, the states must, to the extent possible, offer a parallel response.

In closing, Dr. Lumpkin commented on the CDC surveillance model, NEDSS, which is in the spotlight now, and a recipient of substantial funding support. The NCVHS has agreed that the framework for funding, which began with CDC and has shifted to the states, may weaken the framework that CDC could provide for integrating the systems. Secondly, the NEDSS standards need to be fully specified, in cooperation with the standards setting organizations, the states and other interested groups, including the Consortium. Federal resources should be allocated for state-level technical assistance, and conformance testing should be developed and should be mandatory.

During discussion, Dr. Lumpkin noted that the NCVHS was charged through the HIPAA legislation to recommend standards for the electronic health care commerce pertaining to administrative and clinical data. The Committee has recommended, as the first set of standards, message format standards, with HL7 recommended as the core Patient Medical Record Information standard. The Committee recommends that DHHS endorse those standards by example, such as internal DHHS use and as a requirement that contractors include the standards in any federal contracts. That recommendation is less rigid than the HIPAA administrative standards, and the HHS Data Council appears to be amenable to considering it.

There was a comment that the workforce on the line seems to understand the importance of standards far more than the funding agencies, and that some effort should be made to correct that imbalance in perceptions.

Mr. Ted Pratt observed that the thousands of small public health departments may begin to lose qualified people due to the major money that is flowing into the State programs. Dr. Lumpkin agreed that it was a potential problem and described the Illinois solution, as an example – to hire a technically qualified individual at a competitive salary to work with small groups of four to six local public health departments, relieving the departments of the need to pay fully for a technical person. In addition, the state is working with the University of Illinois to develop a certificate program that should begin to build a stronger workforce for support of the new technology.

American Medical Informatics Association

Dr. William Yasnoff continued his presentation with a review of the American Medical Informatics Association (AMIA) Spring Congress held in Atlanta in May 2001. Dr. Yasnoff oversaw the planning of the meeting, which addressed six major issues related to informatics and public health – funding and governance; architecture and infrastructure; standards; research, evaluation and best practices; privacy, confidentiality and security; and training and workforce development. Six breakout sessions developed recommendations for each area:

Funding and governance –dedicated funding from diverse sources for information systems (not IT alone) was needed and that funding should be assured throughout the life of any project or program; funding should support planning and management structures that could merge the separate but similar models developed by public health and informatics; a business case should be developed for the information systems architecture.

Architecture and informatics – dedicated Internet access should be universally available in the workplace; public health officials should have software tools (and necessary training) to take advantage of the data systems available; the architecture needs an implementation plan, and the development of a public health data repository. In the policy area there should be procedures for monitoring compliance, and implementation of access control measures (security). Although lacking consensus, the AMIA recommended a unique personal identifier to coordinate data integration. Finally, there should be effective communications and workflow arrangements between the public health professionals and the health care community (e.g., the impact of data collection could be minimized by data sharing).

Standards – current data standards should be publicized in the public health community, perhaps on a web-based resource that includes all pertinent groups, issues, etc. Use of the HL7 Reference Information Model (RIM), with ultimately a public health domain data model, the Dwyer decision tables, and models for state regulations and legislation should be promoted to encourage consistency. Using HL-7 guidelines, work to harmonize public health and health care community concepts regarding prevention, disease reporting, etc. Finally, create a fully-specified database for ICD-9 and ICD-10 to make accurate and automated mapping for statistical and billing purposes.

Research, Evaluation and Best Practices – agree on a process for identifying and disseminating best practices and create a repository to encourage a consensus; develop performance standards; create a demonstration program as part of the dissemination process. Evaluation should be linked to the Healthy People 2010 program; existing programs should be evaluated to derive standardized outcome measures. Develop an informatics research agenda using current technology as the base and include multidisciplinary teams in the process. Encourage an informatics component for every new research project proposal and seek new funding to pay for that segment. A lead

research agency should be designated and funded to coordinate research on privacy, security and confidentiality.

Privacy, confidentiality and security – establish several groups (a national forum on privacy policy, community advisory boards, local public health ethics committees). Models for privacy legislation, policies and regulations and a blueprint for a public health data system that includes confidentiality agreements and a privacy board. HIPAA security requirements should be adopted and there should be a review of security for programs in the public health community, including a look at denial of service attacks. Finally, there should be indirect funding options since investment in security benefits all programs.

Training/workforce – existing academic programs should be strengthened, and continuing education and fellowship programs should be expanded. Develop models and guidelines for curriculum (including security) for the existing workforce and accredited academic programs. Promote the development of a career track for informatics specialists.

Dr. Yasnoff concluded that the recommendations fell into two main areas. The first, national governance of public health informatics activities based on federal leadership, inclusion of all stakeholders, to support and promote standards, security and confidentiality, best practices and research. Second, training and education to provide basic skills for everyone involved, and advanced skill training for senior administrators and decision makers. He noted that AMIA had published the recommendations in two major journals (Journal of the American Medical Informatics Association and the Journal of Public Health Management and Practice). Dr. Yasnoff has presented the recommendations to numerous public health agencies and private health care-related organizations.

During the discussion there was a question about what group should create and maintain the web-based resource listing the standards-related activities, and Ms. Greenberg stated that the Consortium's Web-Based Resource Center Work Group was considering the project. In response to a question about the National Library of Medicine (NLM), another possible sponsor of such a resource, Ms. Greenberg said the Consortium was in contact with NLM. Sheila Frank mentioned the US Health Information Knowledge Base (by the ANSI Healthcare Informatics Standards Board - HISB) although under construction to store meta data on HIPAA, could serve as a model for a much broader resource.

Concerning the Robert Wood Johnson sponsorship of the AMIA conference, Dr. Yasnoff explained that the Foundation had expressed interest in public health informatics and had discussed public health issues within the Foundation. The AMIA meeting provided a timely opportunity to become involved with the informatics issue, and the Foundation's interest seems to be continuing.

Mr. Mike Davisson described a New York State project that electronically monitors 30 labs daily to promptly report suspicious infectious disease incidents to the state and to

interested local health departments. The project has been very effective is revealing threats earlier than the manual systems, and monitors health issues such as heavy metal, cancer, HIV-AIDS and pesticides as well. The Emerging Infectious Disease Conference (in Atlanta in late March) will include a presentation on the project. Dr. Yasnoff agreed that publicizing the project is important, noting a similar project in Indianapolis.

Building an Enterprise Model for Public Health Through Partnerships

MHCCM and Beyond

Ms. Rachel Block addressed the impact of HIPAA on Medicaid functions. She noted that states were in a financial bind, and Medicaid matching funds for some HIPAA-related activities were helpful, but there is still a lack of understanding of what HIPAA will eventually cost and there are few line items in federal or state budgets for HIPAA implementation.

Even though state Medicaid agencies will be major users of data, they are generally underrepresented on standards setting groups, partly as a result of lack of funding. Implementing HIPAA Administrative Simplification requirements also involve relatively short time lines. Medicaid's experience in dealing with the Y2K issues, where there was weakness in risk assessment and business continuity planning, provided valuable experience in dealing with some of the information issues related to HIPAA.

The Medicaid HIPAA Compliant Concept Model (MHCCM) was developed to provide tools for state agencies to plan and implement the HIPAA requirements. The initial model is a "shell" that state agencies can customize to fit local conditions and needs. It includes components for data exchange and operations, and a practical tool kit that provides supplemental links to other helpful resources. The model can be applied to other public health enterprises, and public health professionals are invited to review the model at www.mhccm.org and make comments and suggestions.

Ms. Block commented on Medicaid's HIPAA privacy implementation and the exchange of data between Medicaid and the public health offices, noting that the long-standing legal contexts that have applied to that exchange continue in parallel with the HIPAA requirements. Therefore, new processes must be negotiated.

She stated that Medicaid directors do not perceive the value added by HIPAA, even though they are willing to comply. Therefore, it is important to follow the progress of NHII and NEDSS and other programs to identify and bring to their attention the value that can be applied to Medicaid programs. One aspect of that process is to promote federal and state coordination and cooperation in planning and implementing information systems.

Ms. Block concluded her presentation by listing a number of public health areas where state Medicaid and public health agencies are currently collaborating, in various degrees, and where coordination of information systems could provide more positive outcomes: immunization registries, lead screening, asthma and diabetes programs, tobacco cessation programs, breast and cervical cancer screening, and health disparities. Secondly, linking IT to the quality issue provides support for decisions makers (in both policy and health care decisions) and the development of databases that can provide information at several levels: individual, community and population-based.

During the discussion, Ms. Block responded to a question about the State Medicaid Research Files. She stated that the original program allowed voluntary submission of person-level data, which later became mandatory with the Balanced Budget Act of 1997. The National Medicaid Statistics Information System soon to be launched improves on that system. It is hoped that early users will provide feedback that may make it even better.

There was a question about encouraging the lawyers in both public health and Medicaid in accepting the value of data exchange. A study in six states will be completed before the end of the year focusing on legal and operational considerations. That study should provide a basis for policy and training decisions that will make the program more inviting to the lawyers.

It was noted that, when joint Medicaid-public health programs are proposed, the response to participation by Medicaid offices is usually lukewarm. Ms. Block explained that it was the result of budgetary constraints. Focusing on a single issue, such as the immunization registries, might result in a better response, especially if the issue selected was of common interest.

Implementing Systems in Public Health

Dr. David Ross discussed the participation of All Kids Count in implementing enterprise-wide systems in the public health sector. The mission of All Kids Count, established ten years ago, was initially to support the immunization of children. It has evolved into a more global mission of integration of child health programs to create a unified approach to child health care. The mission exposed the group to the challenges of large-scale integration of organizations and people at the state level. The initial approach was to reflect the child's development curve to drive improved health care and services over time.

All Kids Count is making an effort to develop a partnership of practitioners at the state and local level, called "Connections." The group is linked both electronically and face-to-face through meetings and conferences, and has undertaken several specific projects involving core business process, information /data integration, integration of systems that directly support health care (including population-based health care), the promotion of unified person-level public health records and syndromic surveillance.

Dr. Ross discussed implementation processes in the public and private sectors, the private sector being driven by return on investment (ROI) and business methodologies, and the public sector dependent on federal and state funding (where states control the process), developing cooperation among agencies and working within the political framework. Beyond that difference, however, both must face security issues, collaboration across multiple public and private entities, and accountability. A conceptual data model, like NEDSS, must be designed to survive, both financially and operationally, while the enabling technologies shift and change. A major lesson learned thus far is that information technology introduces change, which brings on pain and resistance that must be overcome. It is important in that process to identify the value in the system that will continue to motivate the participants.

Dr. Ross discussed a specific major project in progress and under his management: a feasibility study for developing a public health software repository in an innovative and cooperative way. Some questions hoped to be answered by the study: Can development costs be shared? Is public health software in a unique niche that is inviting to commercial software manufacturers? Can the organization be neutral, non-profit and dedicated to the goals of the whole?

Dr. Ross concluded by inviting comment and suggestion regarding the concept of enterprise-wide systems.

HIPAA and Public Health Issues: Washington State Perspective

Ms. Vicki Hohner, HIPAA Project Manager for WA Department of Health, and Ms. Kathleen Connor, HIPAA consultant with Fox Systems, Inc. formerly with WA Medicaid, discussed the Washington State experience. Public health offices should consider complying with HIPAA requirements even if only some of the data is legally required to conform. One consideration is that some providers are reticent to share data unless assurances are provided that HIPAA privacy and security compliance is guaranteed. Medicaid funding also brings in HIPAA requirements that affect data sharing. Because covered transactions activate HIPAA, all data users must be sensitive to the source of the data.

Medicaid providers will probably be the most complex health care entities that must comply with HIPAA, especially in terms of data codes, reimbursements, etc. The public health care plans should look at HIPAA standards in relation to public health data requirements in order to coordinate data entry as much as possible.

E-forms give providers a familiar format with a HIPAA interface for a variety of transactions. It makes it possible to move data to and from various locations in the system. However, there are many ways to organize information clusters, which can increase the complexity of information handling and make the system more difficult to use.

An E-form interface that replicates the UB 92 format was provided to introduce users to the process. The interface allowed entry of data in a familiar format that, in the background, would be converted to HIPAA-compliant format. The approach, if adopted, would be cheaper and easier to use, especially for small providers who cannot afford a direct HIPAA application. A log-in decision tree would lead the user to the appropriate form and embedded HL-7 standards would reduce the possibility for making entry errors that would violate HIPAA. Conformance testing is a challenge because of the complexity of the law that allows users to interpret the requirements in different ways.

Mr. Dan Demer commented on the California experience with standards, noting that vendors are the weak link in NEDSS compliance. He described the public health integrated messaging architecture, which was developed on the basis that transactions are moving to message format, cost/risk of development is significant, and upgrades must be facilitated. In developing the architecture, because the use of XML and eb-XML is new and not well understood, the process must be a step-wise construction. Considerations also include funding, HL-7 as a work-in-progress, and the fact that faxed forms must continue to be used because the Internet reliability is not perfect. Not all vendors agree that IT is the universal solution to all data management problems. There will also be "gadget" solutions proposed that will distract the process.

Mr. Demer described a NEDSS reporting demonstration across several California jurisdictions that shows the potential of disease reporting using standards (XML and HL-7 in this case), maintaining data integration across the jurisdictions, and in a system that automatically alerts the state's REACT system. The state system, in turn, searches the public health directory (also using standard terms across jurisdictions) and automatically notifies the appropriate public health offices. The system also automatically completes a search of relevant data about the infectious disease threat so that it is instantly available to the public health offices involved.

During discussion, Dr. Walter Suarez commented on the limitation of software provided by Medicaid that allows only HIPAA data to be entered by the provider. There was a comment that additional data (e.g. race/ethnicity not allowed in the HIPAA format) can be appended as a separate HTML tab in the report. He also noted that a provider, using a web-based application to complete a transaction, automatically becomes subject to HIPAA privacy provisions.

March 22, 2002

Call to Order

Ms. Marjorie Greenberg called the second day's meeting to order. She reflected on the presentations of the first day, expressing the opinion that the data standards process is gaining momentum and that there is a clearer understanding of the role of public health in developing standards. However, it was also clear that the role is not well understood and that education is an important aspect of the process in the future.

Vital Statistics

Dr. Pam Akison explained that the National Association for Public Health Statistics and Information Systems (NAPHSIS) operates as a vital records maintenance organization in every state, supporting various public health offices and other users with a wide variety of records services. The Association is moving into electronic processes in certification and verification, including a major contract with the Social Security Administration (SSA) to verify Social Security beneficiaries when they apply for retirement benefits.

The development of electronic death records came into focus on September 11, when the New York City Medical Examiner's Office realized that, had electronic death records (EDR) been established, it would have failed in the face of the infrastructure damage. Before that event, very few state EDR systems were being designed with sophisticated backup and redundancy, even though almost all those involved supported the need for such backup.

Phase I of the NAPHSIS EDR project, funded by the SSA and supported by NCHS/CDC, is complete. The major successes in that phase were the development of standards and guidelines and the creation of functional pilot software for online verification of Social Security numbers (OVSSN). Two jurisdictions (New Hampshire and the District of Columbia) have funded the OVSSN version of an EDR program, and NAPHSIS is supporting both. There is also educational and marketing support available for other potential users (including funeral directors). The OVSSN system was pilot-tested in New Jersey and has been improved to the point where it is a modular system ready for general use by the states. The program can read the state EDR database, monitor changes, and interact with the SSA database for verification.

NAPHSIS is aware that the EDR guidelines and national standards are part of the larger re-engineering of the entire vital statistics data system. The next step is to build use case models and seek buy-in at the state level. There is concern that the cost of the EDR system, multiplied across the states, will be too high. An approach to controlling that cost is a common architectural IT backbone to which states could attach functional components (like the OVSSN), modified to fit the states' needs. As part of that backbone, NAPHSIS will develop a data model that is amenable to modification by the states. Dr. Akison noted that vital statistics data is not necessarily compatible with health

care data, but models could be developed to allow some level of integration. There are several parameters that would be compatible with a web-based system – cause of death, occupation/industry coding, race coding and Geographical Information Systems (GIS).

NAPHSIS is confident that XML is a language that offers benefits for messaging and data sharing, reporting data to federal users, data-sharing among states, and verification of Social Security data (which is already XML-based). The Association has committed to XML and is planning a clearinghouse for XML messaging.

During discussion, Dr. Akison was asked about local storage of vital statistics. Dr. Akison stated that the process will change as local public health offices begin to consolidate data and as access to records becomes electronic. Asked about the process of getting the "underlying causes of death" correctly included into cause of death reports, Dr. Akison said that the ability to build a more interactive process will allow nearly real-time prompts alerting the individuals responsible for entering the report to provide additional information.

HIPAA Update

Dr. Michael Fitzmaurice stated that the Agency for Healthcare Research and Quality (AHRQ) is a data user with regard to health care quality and safety. As a user, the effects of HIPAA standards are important in four areas – transactions and code sets, identifiers, security, and privacy. The Administrative Simplification aspect of HIPAA aims at lowering costs, improving efficiency of sharing administrative and financial data, and protecting person-related health data (privacy and security). The transactions and code set requirements become effective October 16, 2002 (although a one-year extension is available). The first Notice of Proposed Rule Making (NPRM) for the Claims Attachments also are scheduled for release in 2002.

Identifier standards for providers, health plans and employers will be completed before the end of the year, but funding will be required to implement them, perhaps in 2003. Identifier standards for individuals are on hold until privacy and security issues are resolved. The Security standards are nearly ready and should be out in 2002. Privacy rules, mandatory by April 14, 2003, are being reviewed and an NPRM for first year changes (which are intended to reduce the burden of the rule) should be out by late spring 2002.

The Administrative Simplification Compliance Act (ASCA) allows a one-year extension of the transaction rules, which most health plans will probably take advantage of by submitting a compliance plan. The plan must reveal the extent of non-compliance, reasons for that non-compliance, a budget, work plan and implementation plan, identity of contractor/vendors (if any) and a time frame for testing the plan. The plan must be submitted no later than April 16, 2003.

Dr. Fitzmaurice explained that the HIPAA Privacy Rule applies to health care clearinghouses, health plans and providers who submit health data in electronic form to

support HIPAA transactions. The information that is protected includes individual health data shared in any form, electronic or otherwise (e.g. paper), which is held by any covered entity. If individual identifiers are removed, that data is not covered by the rule. Additional information is available on http://aspe.hhs.goc/adminsimp.

Dr. Fitzmaurice listed a few of the items being considered by the Office of the Secretary of DHHS, mainly related to the burden of compliance: prescriptions phoned in to a pharmacy that does not have a patient consent form could violate the rule; hospitals may not be able to obtain patient information for scheduling pre-admissions by phone without a signed consent; the possibility of conversations overheard about patient information may cause a problem; sign-up sheets and bedside charts may reveal patient identity in violation of the rule; and parental access to a minor's protected health insurance data may be blocked.

Currently there are also congressional concerns (in the House Ways and Means Committee) about privacy rule reform: the possibility of grand-fathering in existing patient medical records until patient consents can be obtained; providing more flexibility in the use of medical records by covered entities; allowing reporting to public registries without consent (e.g., cancer registries); sorting out the burden of obtaining patient consent; and concerns about business associate communications, minimum necessary standards, oral communications and state preemptions.

Professional societies are concerned about responsibility for the actions of business associates, who they believe should not be included as a covered entity. The societies want clarification of covered entity requirements, elimination of requirements to mitigate actions taken by business associates, and limited provider burden when the business associate is forced to provide information to patients.

From a privacy and confidentiality perspective, hospitals want revised de-identification standards, the ability to share protected information with other hospitals, and presumed consent to avoid having to obtain a new consent for patients with every provider.

During discussion, when Dr. Fitzmaurice was asked about treatment referral, he stated that referral for treatment is acceptable, but providing patient information to health plans is not. Concerning shared data for research purposes not related to billing, Dr. Fitzmaurice said that IRB or privacy board approval would be required to use data without specific consent. The same would be true if a covered entity wanted to use patient data for research purposes.

Ms. Joy Pritts explained the preemption process for reconciling state regulations with the provisions of HIPAA. The basis of preemption is the ability to overrule state law when it is impossible for the covered entity to comply with both the state and federal requirements. The state law is overruled when provisions of state law are contrary to Federal Regulations. "Contrary to" means it is impossible for the covered entity to comply with both federal and state requirements; or state law is an obstacle to the

accomplishment and execution of the full purpose and objectives of HIPAA privacy provisions.

There is no preemption if the state law is more stringent than HIPAA – greater restrictions on disclosure, greater rights of access for the patient – or the state law provides more information about use, disclosure, rights and remedies. There are specific exemptions to preemption – reporting of disease/injury, child abuse, birth/death and other data for public health surveillance, investigation of intervention. As well, the Secretary of DHHS, on a case-by-case basis, may nullify the preemption in cases of fraud and abuse related to provisions or payment of health care, conflict with state insurance regulations and state reporting of health care delivery or related costs.

Ms. Pritts suggested some steps to determine if preemption would apply. Questions for each state covered entity to ask: Are there comparable provisions in both state and federal laws? Can the covered entity comply with both? Is there no impediment to compliance with the goals of the Federal Health Privacy Rules? Is the state law more stringent? Does state law require certain reporting situations? If the answers to these questions are yes, then preemption would not apply.

Ms. Pritts suggested that in cases of similar state and federal laws, state legislators should consider amending state law to conform to federal requirements simply to make the administration of data management easier for the covered entities.

During discussion, Ms. Denise Warzel expressed concern about approaching state legislators, noting that lobbying efforts must be well thought out and well executed. She suggested that the issue of how to interface with state lawmakers would be an appropriate item for the Consortium to consider.

Asked about the type of state regulation that triggers preemption, Ms. Pritts explained that any state law, regulation, directive or policy that was enforceable in a court of law would be subject to the preemption process. Dr. Michael Millman commented on the difficulty of identifying the various regulations that are involved in the preemption process. He suggested that the Consortium might address that problem. Ms. Pritts conceded that fact, and suggested that first steps might be researching licensing statutes, public health statutes, and evidentiary codes. It was noted that the American Bar Association was interested in identifying the statutes that might apply to preemption.

Dr. Walter Suarez noted that every state has a resource for HIPAA privacy issues. He added that although some registries are mandatory, many are voluntary. Finally, Ms. Pritts suggested that any references available for confidentiality at the state law level would be a good first step in looking at preemption.

United States Health Information Knowledgebase

Dr. Christopher Chute described metadata as “data about data.” The United States Health Information Knowledgebase (USHIK) would allow a user to compare, combine

and use the myriad of data sources in the healthcare data community. Initially, the data sets included in the USHIK will be the leading standard data organizations (SDOs) – X12N, HL7, etc. After providing a brief history of the establishment of the USHIK, Dr. Chute noted that current support comes mainly from CMS, with additional support from DOD, National Cancer Institute (NCI) and the various interested SDOs. Funding has been a cooperative effort, with NCI volunteering to sponsor a pilot site, after which USHIK would maintain a public access site. Other organizations involved in developing USHIK include CDC and NCHS.

Currently the data elements (detailed descriptions of actual data) are from the ASC X12, Veterans Affairs, HL7, the National Council for Prescription Drug Programs, and data elements from HIPAA and NCVHS. There are over 5,000 data elements in the USHIK database.

The goal is to support data sharing, interoperability, comparisons among organizations, and provide a list of data that is available for a data registry. The method is to develop a navigational architecture that links to underlying structures such as data elements, collection of data, agreements, organizations, as well as source elements (products of the SDOs). Dr. Chute used a single data element to describe the experience of exploring the USHIK system. A search would provide comparative information about the data element description (e.g., gender) as it relates to other data models' data. To provide an anchor, the USHIK compares all inquiries to the Australian National Health model, one of the better database models, but one chosen mainly to provide a reference point. Dr. Chute showed a number of ways the data element could be defined and compared. USHIK has prioritized the representation of HIPAA data standards into the data elements registry, which provides descriptions of data interoperability and implementation guides.

The current configuration is designed for human entry of search criteria and it must be data element-specific. On the drawing board is a program that allows a more liberal description of what the user is looking for, which the program will then interpret and provide suggestions for examination and analysis. The computer search will have a much broader information base than the human mind and make the process easier.

A major challenge is the maintenance of the metadata sites, which is currently a very tedious and time-consuming project. NCI is taking the lead to investigate mechanisms to use existing layouts and create an interchange format that can be imported directly into a data registry to make those updates. An advanced prototype data registry has been developed, although it is not yet on the USHIK site. The ability to manage many data elements is next on the agenda.

Dr. Chute mentioned that there is now a difference of opinion regarding the ISO 11179 data standard methodology. One group of agencies has chosen an Oracle process and another group has chosen an open-source public mechanism for metadata access. The resolution of the conflict will answer the question about management of the product and the business model that will determine the next steps.

During discussion, Dr. Chute was asked about NEDSS and he explained that the NEDSS data elements had been harmonized with the HL7 structure, which provides an indirect link with the USHIK directory. But the NEDSS data elements are not directly incorporated into USHIK.

There was a suggestion that if all the data were in ISO 11179 format, it would make it easier to update the site. The ISO web site provides extensive information on how to do that.

Finally, there was a question as to whether there was a collection of data sets similar to the USHIK data element sets anywhere in the known cyber world. Dr. Dorothy Webman noted that several sites exist that offer that information for specific areas (for example, she has created a site for child welfare, juvenile justice and special education). There is also a registry in Michigan that has extensive information on research data sets and federal data sets, but there are still major gaps in identifying a universal site.

NCHS Metadata Registry

Mr. Lewis Berman pointed to over 40 years of collected NCHS survey data, much of it available on the NCHS web site, but almost none of it labeled in such a way that any meaningful search or integration of data is possible. An NCHS internal committee was established to look at bringing some cohesion to NCHS various survey data. The committee looked at several approaches to creating a registry or index – the data, the data sets, the publications involved – and decided to use an information discovery process. A broad range of experts has been assembled, some on the committee, some independent consultants, to address the issue.

Business requirements were at the top of the agenda. The current help desk at NCHS is dedicated and efficient, and the individuals know the "table of content" and how to find what the inquirer is seeking. However, they are not familiar with the actual data, surveys, etc. And users are now expecting online access with search capability, although much of the data is simply not compatible with that approach. Some surveys, like NHANES III can be adapted to such an online approach, but is almost no way to adapt the earlier surveys for any comparison or integration. It would have to be done manually.

The Committee decided to refocus on the metadata about the content of the NCHS web site. One alternative was to adapt the Government Information Locator Service (GILS), a database with locator records about the web site content, which could be integrated with other agency sites to widen the availability of the resources. NCHS would enter information on the numerous data sets that have accumulated over the years. The interface would be a simple word search plus a data set description (subject, author, title). The GILS would return web site referrals.

The result would be more readily available information, and a higher level of user trust that a search would be successful in locating references. There must also be help in navigating the data that is confidential. Finally, there must be a high level of service to

internal NCHS users – probably a different level of service than that available to outside users.

If the GILS effort succeeds, the next step would be a registry or clearinghouse, followed by an effort to build an accessible inventory of the majority of survey data already in the system.

In response to an inquiry, Mr. Berman stated that NHANES IV data, which is now on a two-year sample basis, should be released to the NCHS site in June. There was a comment that the states might benefit from a similar metadata analysis of data collected at that level.

Mr. Elliott Stone commented that, at the state level, there was a need to have not only the availability of a data set, but some extended identification to allow users to apply the data more effectively. Mr. Berman noted that the guidelines – like a cheat sheet – would help users contact the originator or other resource.

Standard Data Organization Updates

ANSI X12

Mr. Robert Davis explained that X12 data content is not necessarily controlled by the X12 committee – it is mainly a messaging function. He explained the X12 organizational structure and noted specific issues related to the X12N current implementation guides (the 4050 version) and other implementation issues (which apply to the 4010 addenda). He noted the development of an X12 standard implementation guide for public health and the development of a partnership with Medicare and Medicaid Managed Care. During discussion, he was asked about the participation of organizations working on performance measures. Mr. Davis stated that, in the X12N process, the health care task group, those organizations are not well represented. Dr. Suarez agreed that they were also not involved with the SDO, HL7.

HL7

Ms. Penny Sanchez discussed HL7, which is primarily concerned with electronic exchange of clinical data. The attachment special interest group (ASIG) within HL7 includes people who participate at the DSMOs, X12 and HL7, building a strong relationship between X12 and HL7. This is mainly due to HIPAA. HL7 is part of the Designated Standards Maintenance Organizations (DSMO).

HL7 is involved in the HIPAA attachments special interest group (ASIG), concerned with claims attachments, post-audit review and reporting and quality measurements. The ASIG involved the health care industry in the process – including clearinghouses, vendors, providers. There has been some agreement that administrative data belongs in the X12 milieu, while HL7 attachment messages should contain clinical data. Thus far, six attachment guides have been developed – clinical notes, ambulance-related data,

rehabilitation services, emergency department, medications and lab result data (all use the LOINC coding). Attachment booklets currently being developed include home health and durable medical equipment. Future attachments being considered are consent forms, children's preventive health and dental.

Outside of HIPAA, the ASIG is involved with NEDSS and the development of standards for Medicaid, public health and end-stage renal disease.

Ms. Sanchez discussed several challenges – maintaining integrity of data and individual privacy in the data sharing process; trying to coordinate data collection processes among the various groups (especially X12 and HL7); providing education to professional providers who are not comfortable with HL7's complexity; and developing a commitment to long-term standardization of data.

During discussion, Dr. Roxanne Andrews expressed concern about the migration of clinical data out of X12, when some clinical data, as part of the claims attachment, may be lost to the public health interests. One major issue is the determination of what is clinical data and what is administrative data.

National Uniform Billing Committee

Ms. Donna Pickett explained that the NUBC was responsible for the maintenance and update of the UB-92. Twenty percent of US hospitals remain on paper billing. The moratorium on changes to UB-92 has ended and discussions have begun on transitioning to UB-02, under which public health will play a more important role. The UB form is used by more groups than just billing – research, public health and health care delivery services. The current committee of 20 is composed of providers, payers and public sector representatives (two from public health). The Committee deals with routine billing changes and DSMO change requests, and works on UB-02 (which will eliminate state fields). The NUBC is pleased to be an integral part of the Consortium and important points made by the Consortium are often considered by the Committee.

The Consortium has agreed that it must present a united position when requesting new or revised codes. Data needs must be clearly defined, and the Consortium must carefully research NUBC change requests, and remain vigilant about pending change requests. The Consortium must be vocal about important issues and remain involved in the process.

National Uniform Claim Committee

Dr. Walter Suarez commented that the NUCC is looking farther ahead than the billing group because few states are collecting clinical encounter data. The NUCC, like the NUBC, is a data content committee, officially a DCC. The Committee reviews change requests monthly (focusing on the data content aspect of the request), and is the maintenance organization for the health care provider taxonomy code set. The

Committee is working on the CMS 1500 form and is a member of the DSMO steering committee, which makes final decisions on all change requests.

The health care taxonomy code set will be officially published shortly and will specify the type of provider reported in the transaction. Currently every claim needs a taxonomy code although this will change from a required element to a situational element. The Committee has developed a process for updating and modifying the code set and accepting change requests.

Dr. Suarez discussed the CMS 1500 form, noting that the NUCC had agreed not to modify the form, explaining that the Committee would look at the best uses of the form in the future. Finally, with regard to gap analysis, an outside consultant provided a report that there is a data content gap, a data specificity gap and an ambiguity gap between data elements. The Committee will address procedures to overcome these deficiencies.

Business Meeting

Ms. Greenberg convened the business meeting. She reviewed the work group reports to ascertain that the Steering Committee, as a whole, would support the recommendations made by the various work group chairs.

The E-Code work group recommended submitting a business case to the NUBC (informally in May and officially in October) for 6 separate fields in the UB-02 for e-codes, allowing the reporting of up to two separate incidents. The members present expressed assent and there were two volunteers for membership on the work group – Ms. Starla Ledbetter and a candidate from CSTE to be nominated at a later date.

The members present expressed approval of the efforts of the Reporting Guide work group. Mr. Davis invited individuals and organizations willing to provide feedback as the process continues to sign up for the work group listserv. The work group will regularly send revisions of the Reporting Guide to the listserv for review and comment. There was a suggestion from the floor that data content definition be included in the work group's agenda.

The efforts of the Web-Based Work Group were supported by the members present. Ms. Greenberg noted that local public health departments would be a major target for the content. Dr. Ana Orlova suggested that an additional product and audience be considered, curricula for schools of public health and medical schools.

Ms. Burke-Bebee reiterated Dr. Claire Broome's remarks of the previous day, that the site should focus on needs specific to advancing PHDSC activities such as identifying pertinent issues before SDOs to the membership and providing the resources to engage PHDSC member in addressing those issues (references and hot links). Additionally, the Consortium's listservs should be used to increase the number of people involved through frequent and effective communication of the relevant issue under review. Commenting on a suggestion that the site should be publicized, Ms. Greenberg noted that the content

was not yet sufficient and the web site had not yet been established, mainly for funding reasons. Dr. Ted Pratt volunteered to contribute the fee for the site URL. Mr. Pratt also requested members to contribute ideas for web site content. Dr. James Gibson suggested adding a detailed glossary of all terms that relate to standards.

Ms. Greenberg stated that a contract was under consideration to develop a resource to provide minutes of all Consortium work group conference calls.

Ms. Greenberg mentioned the Overcoming Barriers work group was just getting started, looking first at overcoming barriers to migrating data to national standards by focusing on emergency department data. She added that Dr. Lumpkin suggested focusing on the emergency department medical record as a beginning for the computer-based patient record agenda. Ms. Love encouraged attendance at the NAHDO emergency room conference in May.

Ms. Greenberg listed new work groups – the payer type work group, which exists but has been dormant; a NEDSS bioterrorism work group; a performance standards work group. A suggestion was made to approach bioterrorism on a slightly broader level, perhaps in the emerging state health IT architecture model (which would include more than just bioterrorism and NEDSS). Ms. Greenberg invited members to participate in a conference call to consider a work group on privacy, confidentiality and security. Ms. Greenberg added a final work group for consideration, on research standards, with a focus on cancer standards.

Ms. Greenberg closed the business meeting by suggesting the need for increased financial support and volunteer participation for the Consortium, the Steering Committee and the work groups.

Encouraging Partnerships to Finance the Consortium's Agenda for Public Health and Research.

Learning from others

Dr. Don Steinwachs discussed health services research, which is not well understood by most Americans. He compared the historical experience of health services research to the progression of the standards movement, including the desire to widen the audience of users and improve the timeliness of information.

The health services research community, relatively strong in the sixties, had lost two-thirds of it financial support by the eighties. The Association for Health Services Research was begun at that time, on a shoestring, and it had elements that the Consortium might consider as it evolves. AHSR has both individual and organizational members, and both pay dues. There is a public/private partnership as a result. As the ASHR developed there was an initial failure to communicate, which was overcome by a program to bring users and providers together in face-to-face situations. It has been clear that a

special concern of the public has been safety, which has its importance in the way public health data is managed and how policies are developed in the Association.

Other ASHR successes relate to arriving at a definition of health services research that is germane to the public interest. That definition and the identification of important problems that relate to human illness and injury might then resonate well with the American public resulting in support for Association projects. A mission statement would also be helpful if it identified problems that should be addressed.

Concerning funding, resources directed at public health are extremely fragmented and any effort to develop more focus on the most responsible organizations and agencies would benefit the Consortium.

Mr. David Helms stated that the Coalition for Health Services Research receives funding from foundations and federal agencies. The Coalition board is composed of Coalition members and members of the Academy for Health Services Research and Health Policy, its sponsoring organization. An advocacy committee develops strategy, supports staff and reviews public statements. Mr. Helms mentioned there are over 3,500 members and 115 organizational affiliates, all of whom pay dues. The Coalition also conducts fund raising programs to supplement dues income, both for the Coalition and for other health services research programs.

There is a project to assess the state of funding for health services research (including a review of the NIH budget of $620 million). There is a project, called Broadening Understanding and Support for the Field, designed to enhance the education campaign mentioned above.

Finally, the Academy has a project of documenting the impact of HIPAA and developing a policy position related to that impact. It is felt that HIPAA presents a threat to the field of health services research in that providers may become reticent to share data. In conclusion, Mr. Helms discussed the National Program Office Model that could, if funding were available, provide technical assistance and support. He added that developing partners is important when making an effort to implement programs and garner funding. It is also helpful to have partners include support for the Consortium's issues when testifying for other purposes.

Dr. Andrews commented that it is difficult to get health services researchers interested in data standards. Mr. Helms noted that many health services researchers rely on medical records data. He added that investigator-initiated research is an important part of total health services research, even in face of the growing trend of sponsor-directed research. Dr. Fitzmaurice commented that access to data is as important as access to funding, and freer access to data ultimately reduces the cost of research. You don't have to reinvent the wheel. Ms. Kathleen Cook noted that the majority of data developed at the local level does not rely on data standards, especially national standards. There is a duplication of effort in designing data systems at that level. This reinforces the need for national standards from a simple economic standpoint.

Expert Panel

Mr. Elliot Stone introduced the Expert Panel. He noted that the business problems must be defined, and one is that the NHII is poorly funded, and that is a focus of the panel discussion. Secondly, the needs of public health research are often not heard in the development of electronic data standards. One aspect is that the research segment is behind other groups (payers, providers, hospital organizations) in understanding and using standards. Another important theme is the concept of entering data once for the benefit of multiple users. And the HIPAA provisions may threaten access to data for research purposes.

The current Consortium is a loose organization without the benefit of an organizational structure to collect funding and use it. This has been accomplished through the NCHS. One concept is to rely on the funding of a member organization for a particular project or part of the Consortium program. Another possibility is to create a legal entity, perhaps a 501C3 or 501C6 entity, to provide an organizational framework for the Consortium's work. Mr. Stone described the business plan process that the work group would rely on to move the Consortium forward. Appropriate funding resources would be identified for various projects submitted for consideration.

Dr. Suarez discussed the questions to be considered by the expert panel. He provided a Consortium mission statement, questions about structure and the types of projects that may be appropriate for the Consortium to consider. The Panel was invited to offer feedback on the questions and any current Consortium project, and to discuss the needs of their own organizations in the data standards area.

Dr. Linda Bilheimer commented on the business plan from the point of view of a funding organization. There should be a legal entity that includes specific responsibility and accountability for the funds and the contract terms. A simple 501C3 organization could be that entity. Although a favorable asset, the question of endorsements from Consortium members relies on whether the Consortium can convince the funder that it has the structure to fulfill the obligations of the grant.

Funding for core support will probably not come from Foundations, nor will funding for projects that are perceived to be the fiscal responsibility of the state or federal government. The RWJ Foundation may temporarily fund projects to engender interest on the parts of state and local agencies. The Foundation also has a major communications component to inform others about areas of interest.

Another aspect of the business plan that caused some concern was the implication that the Consortium might seek funding from vendors, which could become a slippery slope. The Foundation is interested in the broader aspect of standards that helps state and local agencies function more efficiently. IT products are an important part of that, and vendors

are proliferating to offer solutions with a wide range of quality. Those vendors who are willing to provide funding may have a conflict of interest.

Mr. Malcolm Williams explained that Grantmakers in Health is composed of health foundations that work together to discuss issues related to funding and other common interests. Concerning the business plan, he agreed that having a 501C3 status would make funding easier, but partnering with other organizations (that would provide the legal entity) would be acceptable as well. He agreed it was rare for foundations to provide core funding, but he noted a small group emerging that would do just that. He also agreed that foundations are reticent to fund projects that should be funded by governments.

It is important to remember that there are a wide variety of foundations with very different missions and requirements. There are also many smaller, regional and specialized foundations that fund limited projects within a narrow interest range. Finally there are foundations that may not be able to fund major projects, but are willing to support peripheral activities, like the annual Consortium meeting.

The Consortium's approach to funding could be enhanced by looking at some of the smaller foundations that fund specific areas of interest and perhaps funding in specific geographical areas. Foundations also have assets such as experience in a particular area, the ability to support the design of business plans that can be accessed early on, even if the foundation is not the ultimate funder.

Finally, there should be a well thought out tactical plan for approaching a funding organization, based on the foundation's requirements, mission, philosophy and any other information that can be uncovered. For example, regional foundations may be more interested in educational grants.

Ms. Janet Machibroda explained the mission of the eHealth Initiative, to promote improvement in health care quality, safety and cost effectiveness through technology. The members include providers, vendors, and non-profits in the industry. The group seeks to raise awareness of IT potential and to reduce barriers to clinical data standardization by creating better economic incentives for quality care through information technology.

Concerning the Consortium's mission, Ms. Marchibroda expressed admiration for the goals, but with the major funding available now, the Consortium needs leadership and unification. A strong public health based infrastructure should be built and broad member support should be obtained – sharing related products, unifying policy and lobbying where possible.

The question of meeting eHealth Initiative's needs suggests partnering with the Consortium in a public/private collaboration, exercising the enormous power of the members, participating in an advocacy campaign for promoting national data standards and building the NHII. The Consortium could help define what works in reaching the

consumer with the data standardization message. There is also a need to develop data for decision makers. The extra funding available now could be leveraged if a data standards component was part of each funded project.

Finally, the eHealth Initiative believes government can provide incentives and the private sector can influence the process in the marketplace. Identifying the needs of both public and private organizations helps develop an approach that would provide a quid pro quo.

Dr. Andrews explained the AHRQ operates at a broad national level to support health services research and improvement in quality of care, but also at project levels, such as the Healthcare Cost and Utilization Project (HCUP). As part of its broad mission to improve data for health services research and quality improvement, AHRQ has provided some funding for the Consortium meetings, and has some conference-support money to support meetings related to AHRQ's mission. The Consortium might also look at collaboration at the project level. For example, there might be some support available from the HCUP project through the project's contractor in areas that are of importance to both HCUP and the Consortium.

Dr. Millman recalled an experience with David Helms that came out of the cancellation of the Health Planning Program some twenty years earlier, where some of the resources developed during that program were translated to other programs and finally resulted in establishment of the Academy for Health Services Research and Health Policy. It is now very difficult to find funding for the infrastructure of an organization like the Consortium. Nonetheless, funding can be available through program-specific projects. There is now funding for health care reform, most of which is going to the states, but the Academy did manage to receive some funding from that for technical support.

There is a lot of data collection going on at various levels and the Consortium may want to consider selecting a narrow focus for which there is funding available for specific technical services.

Dr. Steve Steindel explained that CDC assessed its work with SDOs in early 2001 with a plan to address the issue in September, a process that was understandably interrupted. That process is back on track and much of the work is done through partnering organizations. The Consortium is a potential partner for similar projects. It would be easier, however, to establish that partnership if the Consortium was a legal entity.

Dr. Steindel discussed CDC needs related to data standards, NEDSS, the expansion of NEDSS, and the NHII. Now there is a need for practical solutions, developing state-based materials for support of health data standards. Another need is a process for monitoring a number of organizations (e.g., the possible removal of birth weight by the DSMO). There is also a need for groups to complement, i.e., provide some component of support, for projects and programs CDC already has under way.

Summary

Dr. Edward Sondik stated that the greatest achievement of the Consortium might be its very existence and the effort to bring public health needs to the forefront. He suggested that the legal entity previously mentioned might be an appropriate move, while expressing continuing NCHS support for the Consortium.

He commented on the Consortium's name, noting that two words had special connotation. Data standards was the foundation of the effort, but he felt that the word "public" in public health might be a constraint. He suggested using just the words, "Health Data Standards." He ventured the opinion that few really understand what public health really means, including some in Congress.

Dr. Sondik urged the Committee to think in terms of needs. The electronic medical record may not have a real organizational champion anywhere in the public health community, and perhaps the Consortium could consider that role. If the Consortium became a C3-C6 entity, and adopted that role, it would mean the need for developing funding outside the NCHS.

In summary, Dr. Sondik said that the Consortium should not limit the scope of its mission when developing its future structure. Until now it has been a value-added adjunct to NCHS in terms of broadening vision, increasing knowledge and providing mutual support for those involved in the data standards process.

Adjournment

Ms. Greenberg expressed appreciation to the NCHS for the support of the past three years, and for the volunteers who have participated. She adjourned the meeting at 3:00 p.m.

Attachment

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