Minutes of the 4th Annual
Public Health Data Standards Consortium
Steering Committee

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Welcome
Marjorie Greenberg, NCHS/CDC

Marjorie Greenberg opened the Fourth Annual Steering Committee meeting, "The Consortium at the Crossroads," welcoming representatives of the 38 member organizations and expressing appreciation to the sponsors who made the meeting possible. She described the aims of the meeting – to review accomplishments, discuss future plans, set priorities for the coming year, share information and continue to identify the needs of the member organizations.

Ms. Greenberg briefly noted the continuing standards momentum, including the impending HIPAA implementation of the transaction and code set rule and the privacy rule. The CDC had launched the Public Health Information Network as implementation of NEDSS continues as part of that Network. The E-Health Initiative completed implementation guidelines for standardized reporting in a number of important areas.

The Consolidated Health Informatics Initiative (a project of HHS, DoD and the VA) seeks to establish federal health information interoperability standards, recommending four messaging standards and one vocabulary standard. Several vocabulary work groups are developing recommendations for medications, interventions and procedures, demographics, immunizations, lab results and clinical encounters.

Discussing the Consortium's priorities during the past year, Ms. Greenberg pointed to the Health Care Service: Data Reporting Guide, development of a first generation Web-based Resource Center, and continuing focus on securing funding. She noted that, concerning funding and future structure of the Consortium, a Business Development and Marketing Work Group had been established after the last annual meeting, which recommended transition to a non-profit corporation, a process that has begun. Secondly, after the last meeting, two new work groups were established -- a National Health Information Infrastructure work group (which will begin by looking at emergency department data systems) and a work group on privacy, confidentiality and data sharing.

Ms. Greenberg briefly mentioned the standing work groups, expressing appreciation to those who chair and otherwise support the work groups: Bob Davis, Tom Doremus, Elliot Stone, Walter Suarez, Barbara Rudolph, Jonathan Lawniczak, Arturo Coto, Amy Bernstein, Judy Parlato and Murray Sagsveen She also thanked those who served on the National Uniform Billing Committee and National Uniform Claim Committee and the NCHS staff, who have worked diligently for the Consortium.

Finally, Ms. Greenberg invited the members to consider ongoing challenges – solidifying the Consortium, strengthening partnerships, encouraging member participation in the work groups and generally spreading the standards message. She added that there was an opportunity for the Consortium to become a leader in promoting

a community-wide standards-based information infrastructure, integrating programs across the entire public health/health care community.

Report from E-Codes Work Group
Dr. Arturo Coto, NE HHSS

Dr. Coto reviewed the work group's charge, to develop a justification and make recommendations for expanding the collection of external cause of injury codes in the 837 institutional claim form. He noted that the charge was later expanded to include promoting current practice in cause of injury code collection, and assessing and improving cause of injury code reporting in discharge data systems and electronic data reporting standards. After last year's meeting, there were preliminary discussions with the NUBC about additional fields for external cause of injury. There has also been collaboration with the Health Care Service: Data Reporting Guide Work Group on expanding the number of fields available for reporting external cause of injury codes.

Dr. Coto commented on accomplishments, including the addition of five fields for E-Code information in the UB-O2, up to ten in the Health Care Service: Data Reporting Guide. The work group has been collecting anecdotal data on the use of injury codes to be available when the educational program is discussed and when case definitions are considered. Such data has also been useful in looking at surveillance epidemiology, in developing prevention programs and in providing support to lawmakers.

During discussion, Dr. Roxanne Andrews (AHRQ) commented that the Agency's database project, Health Care Cost and Utilization Project, which collects data from more than thirty states, is now considering E-codes. She said that most states are collecting E-codes with or without a regulatory mandate. Ms. Greenberg added that UB-02 has been deferred, pending implementation of ICD-10-CM, which it will support.

Report from Payer Type Work Group
Dr. Amy Bernstein, NCHS/CDC

Dr. Bernstein reported that the work group had been charged with developing a common payer identification system that could be applied across state and local data systems. Current systems are neither comprehensive nor mutually exclusive, and are not consistent from state to state. The work group created a "source of payment typology" (available for review on the web), which is loosely modeled on the ICD system, but independent of the plan ID. There are still questions to answer – who will fund the typology and who will maintain it? Included in the work group plans is review of the HIPAA plan ID system (same as payer ID), but the Notice of Proposed Rulemaking has not yet been published. Dr. Michael Fitzmaurice suggested including CMS in the work group loop. Ms. Greenberg noted two issues related to plan ID – at what level it will be enumerated, and what will constitute the database? Finally, Dr. Millman suggested that there must also be a valid business case that would demonstrate a benefit to industry for participation.

Report from National Health Information Infrastructure Work Group
Dr. Barbara Rudolph, NAHDO and University of Wisconsin

Dr. Rudolph described the charge to the work group, to identify barriers and means to overcome them in the adoption of the standards process. She noted that there is both lack of a clear mandate to adopt national standards and no unified leadership in either the adoption process or development of standards. The work group has relied on the web as an information dissemination tool, focusing on the importance of integration across federal, state and local agencies, and the importance of identifying a lead person in both HIPAA and in data standards. Another barrier is a lack of knowledge in most constituencies about how to get a handle on getting started. An issue is the fragmentation in state and local programs – multiple data collection tools and little agreement on definitions. Finally, there is poor communications and very little coordination. The work group feels that developing best practices models would be helpful to showing the various stakeholders how to begin the process of coming together.

The work group has accomplished some important first steps, including becoming involved in the planning process for a major cancer conference in the fall and stimulating the conference committee to include a short course on data standards on the agenda. A large number of individuals from cancer registries will be exposed to that course. The work group has also been working with NAPHSIS, NCHS and the SSA in the redesign of the electronic death records system, and the development of a white paper on the role of the public health community in supporting the NHII (which will promote the IOM report recommendation of setting up small pilot programs in states to look at creating infrastructure). Finally, the work group is looking at emergency department data systems. Dr. Rudolph encouraged Consortium members to share success stories that might be helpful in the development of the best practices scenarios.

Framework for the NHII
Dr. William Yasnoff, HHS

Dr. Yasnoff referred to a National Committee on Vital and Health Statistics (NCVHS) report that defined the NHII as a "comprehensive knowledge-based network of interoperable systems capable of providing information for sound decisions about health, when and where needed." He made it clear that it was not a centralized database of medical records, federal or otherwise. Ultimately the NHII will provide a way to access health records wherever they are maintained, to support medical care decisions; aid in decision making with regard to health care, research, and analysis of public health (e.g., identification of possible bioterrorism); and provide both quality of care and payment information, and consumer access to personal medical records. The general groups that would benefit are the consumer, clinicians and the community/public health care community. Clearly, for such an infrastructure to exist, there must be compatible standards, messaging and definitions, which would then allow the various state and local medical records databases to communicate with each other. Once worked out, the

patient's medical records would be able to move with the patient wherever health care is provided.

Dr. Yasnoff suggested that the most important benefits of the NHII would be the ability to monitor and protect public health, improve patient safety (by preventing many of the medical errors that occur when physicians are unaware of previous patient care), and the concomitant support that such complete and accessible medical records would contribute to decision making at all levels. There is exceptional support for the NHII, from the IOM (in several reports, including "To Err is Human") to the federal agencies to the President's Information Technology Advisory Committee. In spite of that support, the major impediment to developing the system is the complexity of medical records, which are highly fragmented across the nation, and the subjective nature of many of the components (which has made the progress toward standards more difficult than in other industries, like banking and credit. There is also considerable institutional resistance, partly because there are fewer incentives for physicians, insurance companies and others to participate.

There are a number of requirements to promote progress -- standards are needed, as is capital investment and funding for research to identify and overcome obstacles. Dr. Yasnoff stated that it is important now to inform, collaborate and convene, which his office is doing through a web-based information resource, collaborating with groups such as the Consortium. His office is also participating in planning a national meeting (June 30 through July 2) to develop consensus among stakeholders. That meeting will offer sessions concerning privacy, architecture, standards and vocabulary, financial incentives, safety and quality, consumer health issues, homeland security, research and population health issues.

Dr. Yasnoff commented on funding, which for 2003 is zero (although there is $4 million in the e-health initiative that could be available for an NHII pilot project), and a White House request for $3 million for NHII in 2004 (plus $50 million for demonstration projects). The ultimate goal is to encourage the development of state and local infrastructures that can be connected through the NHII. Although there will not be a federally-mandated program, the federal government can help local programs avoid duplication of effort and sidestep problems others have already solved. Some of the important obstacles to overcome include education of senior level policymakers, coming to grips with confidentiality issues, and developing meaningful incentives, especially for the individual physician, whose buy-in is critical.

NAPHSIS Messaging Project
Robert O'Doherty, CO DPHE

Mr. O'Doherty described the NAPHSIS efforts to develop standard messages to exchange birth and death data, mainly working through the vendor community, which is not very large because of limited funding for the purpose. The vital records involved mainly come from hospitals, physicians and mortuaries. The data accumulated is usually sent to public health departments that maintain local records, the NCHS and the SSA.

The NCHS has developed standard birth and death record forms, often modified by the states (usually adding other information like immunizations).

Concurrently, NAPHIS is working to develop a NEDSS-compatible data model, in cooperation with HL7, an effort that includes trying to create software standards. Thus far, a message format for birth/death data has been developed that is capable of being exchanged. The challenge is now to harmonize that format (the data field definitions) with the HL7 messaging, which is part of the software development process. During discussion, it was noted that HL7 should not be considered the gold standard, but rather a participating standards organization. There was another comment that HL7 had developed a new performance tool to allow users to publish a specific profile of data contents, and the VA has helped create a supplemental tool that helps implement and test the performance tool.

Health Care Service: Data Reporting Guide
Educational Materials and Next Steps
Robert Davis, NY DOH
Denise Love, NAHDO

Ms. Love discussed the Health Care Service: Data Reporting Guide, the standard for reporting health care data at the state level, which is critical for supporting the NHII. She noted that 31 states now collect hospital discharge data. NAHDO is also involved in developing the Health Quality Report and the Health Care Disparities Report, and data will be collected from about 45 states. Ms. Love commented that a number of states plan to convert to the 837 format by the end of the year, which may result in the loss of some fields currently being reported.

Mr. Davis discussed the Health Care Service Data Reporting Guide, noting that it was complete as a first draft, including compatibility with the X12 process and appropriate approvals. The Guide, however, must be seen as a work in progress that will require continuous input from users and periodic amendment. It is especially important to engage the regional, state and local stakeholders in the process, since they are the groups that will provide the data input. The reporting Guide is HIPAA-compatible in the sense that it conforms to HIPAAs administrative claims/encounter standards. The reporting guide differs from the HIPAA claims/encounter guide by going beyond the HIPAA data collection requirements. Some unnecessary data have been dropped from the reporting guide such as certain claims payment data and other required data have been added like race and ethnicity, which supports state and national requirements for reporting purposes. Mr. Davis emphasized the importance of cooperation among the wide variety of stakeholders, including the X12 organization, HL7 (the clinical standards are built into the Guide) and the NUBC. He added that, aside from changes that derive from the users, there would also be changes that came from the inevitable modifications to the HIPAA regulations. Underlining the dynamic nature of the process, he closed by stating a need to educate, engage and energize the stakeholders involved. During discussion, comments were made about data privacy protection issues, especially with regard to the public health community that receives information from covered entities, data which then

escapes the protection of the HIPAA regulations. It was noted that, even so, state and federal protections continue to insure privacy.

Web-Based Resource Center
The Lewin Group and Work Group Members
Christina Worrall, Jed Perry, Allen Kendall

Ms. Worrall described the development of the Web site that supports the Web-Based Resource Center, which was created by the cooperative efforts of The Lewin Group, Social and Scientific Systems, Inc. and the Consortium's Web-Based Resource Center Work Group. The Consortium Steering Committee had approved a framework for the Web-Based Resource Center that included a requirement to build partnerships and develop constituencies for support, active participation in supporting standards development and the eventual implementation of those standards. Goals were established at the outset – to focus on health data standards that were specifically for practitioners in the public health arena and for health services researchers; to develop knowledge resources to educate stakeholders; and to provide a forum for sharing ideas, lessons leaned and best practices. The Web-Based Resource Center also has an important marketing capability to promote the Consortium and its objectives.

The Web site currently has five major sections: an "About the Consortium" section that describes the Consortium and includes a membership recruiting component; an extensive knowledge resource (including data, references, bibliography and links to other important Web sites); an area on the site (not yet developed) for tracking the progress of data standards development, a "implementation case studies section for sharing experiences, best practices and other examples of successes in the standards area; and a sophisticated search engine. The site includes a public health data standards tutorial (nine modules about public health, public health data, data standards, and public health informatics).

Currently the audience for the Web site resource is exceptionally broad, including decision (policy) makers, funding organizations, data collectors, supplies and users. Thus far there has been substantial review by a broad range of experts who have offered many suggestions for improving the site, first through an alpha test that was conducted mainly within the work group, and then a beta test still ongoing, involving individuals outside the work group.

Mr. Kendall came forward to discuss the technical aspects of the Web site and Mr. Perry, using a real-time access to the Web site, demonstrated the various sections above. The site includes a PowerPoint presentation describing the Consortium that can be viewed on the site, downloaded and customized by any interested party. He described the search engine that recreates a search database every 24 hours by searching the entire Web site and all linked Web sites and storing references that can be identified in a word or phrase search. Those Web sites are carefully selected by experts to eliminate as much "noise" as possible (which shows up in universal search engines like Google). Finally,

Ms. Worrall demonstrated the PowerPoint slide show that describes the Consortium (it also includes a recruiting component).

Presentation by Microsoft Corporation

Mr. Ron Ridderbusch, representing the lunch sponsor, Microsoft, expressed appreciation for the opportunity to participate in the Consortium. He noted that Microsoft had, several years earlier, made a commitment to support the health and human services sector in three areas – message processing, data storage and platform services. He stated that ten states have developed systems based on Microsoft technology. Mr. John White, also from Microsoft, commented that the company considers standards a basic element of systems integration, which is why Microsoft has developed off-the-shelf support that should meet more than 75% of data handling needs in the health services industry. He presented a video that demonstrated the potential to integrate data generated by various departments of a state or local government (police, social services, welfare, juvenile services and rehab services) all of which enter data into a linked data system.

Web-Based Resource Center (Continued)
The Lewin Group and Work Group Members
Christina Worrall, Jed Perry, Allen Kendall

Resuming the discussion of the Web-Based Resource Center, Ms. Worrel invited the participants to discuss the initial Web site and offer suggestions for improvements. There was consensus that the PowerPoint presentation and the tutorials were very valuable tools that should be enhanced. Specific suggestions included providing documents in a form that can be edited, as well as in PDF format; graphics that can be easily extracted from whatever document they may be in; and definitions that are supported by references to the source of the definition (since a particular term is often defined in more than one way). There was a discussion about the extent of Web site maintenance and the costs related to maintaining the site (especially balanced against the number of users who will rely on the site). It was noted that the Web site will include many links to other sites, with the warning that users are intolerant of dead links that go nowhere or, worse, links that may end up at unrelated or undesirable sites. There were comments related to enhancing communications with users – message boards, FAQs, a "contact us" capability – and whether those user communications should be edited or otherwise maintained. Finally, it was observed that the site would provide an excellent marketing function, not only for the Consortium, but also for the overall goal of supporting the standards process. Mr. Tom Doremus discussed the submission of individual biographies as a resource for others working in the field to locate expertise in various areas. He noted that it would help promote professional networking as well.

It was noted that the site, which would be formally launched on June 1, was "version one" and that enhancements would follow. During the early stage, there should be an assessment of whether other federal, state and local agencies perceive sufficient value to contribute to its future growth. Mrs. Worrall summarized the participant discussion – a focus on marketing, a first generation site that would evolve through

enhancements, specific functional improvements to make it more useful (more and better documentation, search capabilities, tutorials and educational resources). She noted that initial marketing could include word of mouth, an effort to place the site high on commercial search engines (like Google), a willingness for member organizations to include a link to the site on their own Web sites, participation in various national and regional health-related meetings (booths, displays, etc.) and some initial publicity (a press conference called by a prominent legislator was suggested). Participants were invited to complete a ballot (provided in the meeting materials) to indicate a sense of priorities with regard to enhancements, interactive communications with users, types and sources of data and other information, site management and maintenance, and control of data submitted by users (such as case studies, best practices, etc.) and other Web site-related issues.

Finally, there was a discussion that resulted in agreement that both a business case, to justify the expense and effort, and a business plan, to frame the process by which the anticipated results would be attained, should be carefully constructed, especially before substantial financial commitment is finalized.

The Future of the Consortium
Dr. Walter Suarez, MCHE
Elliot Stone, MHDC

Mr. Elliot Stone introduced the discussion of the "new" Consortium by expressing appreciation to Ms. Greenberg for her leadership in organizing and supporting the Consortium since its beginnings four years ago. He announced that four important documents would be discussed: the Consortium Articles of Incorporation, the new corporation's bylaws, the business development plan and the new corporation's financial statements.

Dr. Walter Suarez explained that the incorporation process was recently begun in Minnesota (filing the Articles of Incorporation and the by-laws) and the new non-profit organization, which was authorized to conduct business in accordance with current law and regulation, came into being. The regulations require that the corporation have a named board of directors and officers. The purpose of the new corporation is to promote and/or conduct educational research and charitable activities. The next step is to secure from the IRS a designation of 501(c)3 status, which is related to receiving tax-deductible contributions.

Dr. Suarez stated that the participants would be invited to discuss the by-laws in small breakouts to insure that they reflect the members perceived goals and objectives of the Consortium. He noted that, as currently composed in the by-laws, the make-up of the board of directors would reflect the general membership: representatives of federal agencies (four votes), state and local governments (four votes), professional membership organizations (six votes), other professional organizations (two votes), academic institutions (three votes), supporting members (two votes). There would also be a class of membership, individual, which would not be represented on the board. Each category is limited to the number of votes allocated in the by-laws, but the number of individuals

appointed to the board for any category may exceed that number. In that case each board member in that specific category would be entitled to cast a fractional vote determined by dividing the number of individuals into the number of authorized votes.

Mr. Stone explained that, now that the Consortium is a legal entity, the next step is to allow organizations to join as "founding members" or, for a lesser contribution, as "general members." Founding members would be appointed to the board of directors, and would become "contributing members" in subsequent years. Funding to support the Consortium's work will also be solicited from other "non-member" sources (organizational support contracts, grants, endowments, etc.) and, perhaps most importantly at the outset, from an "incubator" organization.

Mr. Stone explained that the Business Development Work Group had developed a list of potential incubators, which had been reduced to two – the Public Health Informatics Institute (PHII) and Johns Hopkins University. Dr. David Ross (PHII) and Dr. Anna Orlova (Johns Hopkins) briefly discussed their institutions' qualifications to provide the incubator support (administrative infrastructure) that would allow the new non-profit Consortium to become operational both efficiently and quickly. The Consortium could then begin it mission work immediately without concern about office space and equipment, administrative staffing and other details related to setting up a new business.

[The participants recessed to form small discussion groups.]

Report of Roundtable Discussions
Dr. Walter Suarez, MCHE
Elliot Stone, MHDC

Mr. Stone invited the rapporteur from each breakout group to comment on the provisions of the by-laws or make other observations appropriate to the new organization. Concerning the funding of the Consortium, it was observed that approaching the states (rather than individuals) to become members would probably more effective. In the financial statements, in which state and local health departments were combined, it was believed that local health departments should be approached independently since there may be different perceptions of value of the resources of the Consortium. That is, in marketing the membership, each group should be approached with special regard to perceived value. There would be common benefits, however, such as access to correct and current information about the standards development process, and the fact that the Consortium would be aware of and sensitive to the variables related to public health and administrative databases. Concerning the use of grants, one breakout group agreed that the cost of obtaining and administering the grants should be considered in the net effect of the funding, since those costs can be substantial and dilute the benefit. Finally, the Consortium should be sensitive to the fact that federal funds support state and local agencies and some mechanism to facilitate use of those funds for membership (e.g., set-asides) would be appropriate.

Another breakout group focused on value, noting that the Consortium may be the most efficient vehicle for state and local agencies to stay abreast of developments and avoid duplication of effort, both of which can effect cost savings. Additionally, the Consortium will have credibility at the national level, will be able to facilitate interoperability and integration efforts at the state and local level, and can stand as a major influence as health care issues become more and more politicized, especially as health care costs continue to rise and insurance coverage falls. Similarly, as that occurs, it is important that the Consortium continue to broaden its membership and influence in the private sector.

Report from Privacy, Confidentiality and Data Sharing Work Group
Jonathan Lawniczak

Mr. Lawniczak, after describing his affiliation with the Coalition for Health Services Research, reported that the work group had conducted several conference calls that resulted in the work group's charter. A major aspect of activity will be providing a forum for sharing ideas and experiences related to privacy, confidentiality and data sharing. Hopefully it will result in the accumulation of case histories and anecdotes that will be helpful when future review of the HIPAA regulations occur. The work group intends to work closely with the Office of Civil Rights to keep Consortium members up to date.

Members of the work group expressed concern about obtaining data from covered entities that may rely on HIPAA to deny such access, especially since there is little incentive to provide data. Mr. Lawniczak stated that the work group was in the process of developing an agenda for the next year and would welcome additional participation by Consortium members.

During discussion, a number of issues and concerns were mentioned, including concern among public health officials that the accountability requirements for disclosure of data will be onerous. Another impediment is the interpretation of the regulations by legal counsel in public health departments that may further mitigate their willingness to release data. Finally, the whole issue of hybrid entities must be approached through interpretation of the regulationss. It was suggested that analysis of the FAQs located on various organizations' Web sites might be an appropriate work group endeavor, especially to identify differences in interpretation of the regulations.

HIPAA Update – Standards and Privacy Rule
John Young, CMS
Kathleen Fyffe, OCR

Ms. Fyffe briefly reviewed the history of concern in the health care community over rising administrative costs, noting that the concern extends back nearly twenty years. She noted that WEDI (convened by DHHS Secretary Louis Sullivan in 1991) had been very effective as a policy advocate. She added the Consortium is in a position to be similarly effective.

During discussion, she stated that materials were being carefully reviewed and would be released soon that would provide understandable information about the privacy rule for targeted groups in the health care industry affected by the rule – providers, health plans, clearinghouses, state and local governments. Concerning the Privacy Work Group's concern about access to data from covered entities, she stated an opinion (based on recent conversations with the American Hospital Association and other affected organizations) that working out the details of access to records may take some time, perhaps years. As far as the Office for Civil Rights addressing that concern in the immediate future, Ms. Fyffe commented that the most pressing concern is now the anticipation of the complaints that may begin to appear after the April 15 effective date, especially since patients will be exposed to privacy notices that explain their right to submit such complaints.

Ms. Fyffe briefly discussed enforcement, noting that there were funds set aside for the Office that could be used to support that philosophy of enforcement, which is cooperation and assistance. She added, however, that the statute does provide for both civil monetary penalties, under the Office for Civil Rights, and criminal penalties, under the Justice Department. Ms. Fyffe closed by encouraging the Consortium to review the accomplishments and the process of WEDI, a non-profit organization that relied on thousands of hours of volunteer support, just as the Consortium may do in the future.

Mr. Young, from the Office of HIPAA Standards, described his organization that has three divisions – enforcement, regulations and outreach. The goal is to encourage voluntary compliance by developing protocols and other materials to assist organizations to conform to the regulations. Currently, the Office is in transition from it early effort to simply explain HIPAA, to developing answers and support for very specific technical questions about compliance. Unhappily, although some covered entities have made good progress (mainly the larger organizations), a great number are still basically unaware of HIPAA, especially small organizations in rural, urban and suburban areas (including many Part B providers and physician groups). The leaders in the field are Blue Cross/Blue Shield, and American Hospital Association, and the larger clearinghouses and software vendors.

There is still an education component to encouraging compliance, but risk assessment and gap analysis, explanation of a cost/benefit strategy and development of policies and procedures, and the testing requirement are increasing concerns for covered entities. It is important to communicate that the covered entity has the primary compliance responsibility and not subcontractors, vendors, clearinghouses, etc. The testing requirement applies to interactions between covered entities to ensure that data interfaces work and communication is effective.

Public Health Information Network
Dr. John Loonsk, CDC

Dr. Loonsk discussed the Public Health Information Network (PHIN) from the standpoint of it relationship to bioterrorism. Noting the fragmentation of the health care system information technology, he pointed to the need to coordinate data transfer, especially with regard to functional integration. He stated that the CDC Director has expressed the vision that the Network serve as a framework for that coordination, which has a positive aspect (clear identification of the network as the primary mechanism) and a negative aspect (the possibility of excluding some IT components that are not within the network's parameters. Therefore, the objective is to develop a way to enable integration of all other good work that exists in various areas other than the health sector.

When linked to bioterrorism, which often involves an emergency situation, it is best to establish and test the system during normal times. And the system must support the various users, some of whom are still in the paper forms mode. It is important that, when an emergency occurs and the bells and whistles are going off, that the public health user's response is not impaired by limitations in the IT area in which he/she works. Currently, the communications system relies heavily on telephone and e-mail communications, point-to-point communications.

In a biological threat situation (e.g., a suspected smallpox case), there is much more information required than the typical first response situation, and there is a concomitant requirement for security in transmitting information to various interested parties at different stages in the process, from tight need-to-know security when the situation first develops, to major efforts to communicate with the public if the threat proves valid.

The Public Health Information Network has the potential to be an effective communications mechanism. The steps to get there begin with identifying relevant industry standards, developing specification within those standards, creating tools to achieve those steps, and developing transitional software (which must be free and widely available) that allows implementation of the standards. Key developments include designing and implementing a systems architecture that will interface with other public health organizations. This involves (among other needs) security, standard data exchange, identifying participants, standard messaging, standard definitions, data models that can be integrated with other data models, delivery of content, web query capabilities, a certain level of automation of data analysis, and the use of shared systems, all of which involves partnering with a number of other interested groups.

During discussion, Dr. Loonsk briefly discussed the need to develop standards for timeliness of data and the transfer of data in real time. He also commented on the importance of making the standards as unobtrusive as possible to other systems, and developing software mainly by working with the public health organizations rather than the software vendors. The focus will be on the process of developing compatible systems and models that favor integration.

Work Plan for the Consortium
Dr. Walter Suarez, MCHE

Dr. Suarez stated that the new corporate documents (Articles of Incorporation, by-laws, business plan with financials projections) would be sent to each Consortium member. He noted that the Consortium is a unique confederation of state, local and federal organizations interested in the development of public health and research data standards, which would focus on education and advocacy and the standards development and implementation process.

He reviewed the discussion of the previous day and the results of the ballot completed by members regarding the web-based resource. There was support for the concept of representation by all major member groups on the board of directors, and the concept of taking advantage of an incubator "sponsor" during the initial start-up. Dr. Suarez commented that there would be consideration of the needs of the states with regard to making a positive contribution when funds might not be readily available to support the dues requirement – services in kind, contribution of legal resources, participation in a specific project, etc.

It was agreed that perhaps the most important first step is the marketing of the new Consortium and its Web-Based Resource Center, followed by refinement of the business plan. Concerning the ballot that related to the Web site, marketing was also considered a top priority, as well as enhancement of educational materials (especially the tutorials), and a continuing focus on functionality enhancements and quality assessment.

Dr. Suarez reiterated the structure of the board of directors and the categories of membership. There was a comment that the CDC Office of General Counsel should review the structure. Concerning the contributions of the incubator group or groups, he explained that the basic start-up infrastructure would be considered an in-kind contribution, but that certain contributions (such as funding a full- or part-time executive director) would probably be reimbursed later, and that the incubator might also contribute as a founding member.

Ms. Greenberg discussed the role of NCHS, which has been the primary financial support for the Consortium, noting that certain support would continue (e.g., support for the work groups, certain meeting expenses, etc.). Staff positions, currently covered by NCHS staff, would be supplemented by employees of the corporation, as well as volunteers in the new Consortium. Dr. Steve Steindel (CDC) commented that the new Consortium should have greater opportunities for fundraising and could count on CDC for the same kind of support proffered other professional organizations (cooperative agreements, indirect funding of projects, etc.).

During discussion, it was noted that the organization would begin to function by July 1 (which would be the beginning of its fiscal year), although it was understood that it would take additional time to come up to speed. It was felt that getting the new

Consortium off the ground would allow establishment of the board of directors and an executive committee, both of which would be important in early negotiations of any contract. There was a comment that the Consortium should be structured in such a way that it does not compete with any of its members for specific funds. In response to comments that the states may be especially limited in the ability to pay dues (some states have established moratoriums on joining organizations), Dr. Suarez pointed out that the budgeted income from states was very small by comparison to other sources.

In conclusion, Dr. Suarez described next steps, which consist of consolidating the new Consortium's structure, securing the first round of funding through membership fees, identification of the incubator partners, establishment of the board of directors, and initial staffing. The core functions will continue – education and the Web-Based Resource Center, and participation in the standards setting process through representation in the various standards setting organizations.