Public Health Data Standards Consortium
Strategic Planning Meeting

Summary of July 17, 2001 Meeting

Prepared for:

The Public Health Data Standards Consortium

Prepared by:

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A.   Overview

The Public Health Data Standards Consortium is a coalition of organizations committed to the promotion of data standards for public health and health services research through the collaboration of State, Federal, and private sector organizations. It convened this Strategic Planning Meeting to provide guidance to several new work groups established at the Consortium's March 2001 Steering Committee Meeting as part of its overall effort to implement the Consortium's new education strategy. The blueprint for the Consortium's overall education strategy was articulated in a May 2001 report prepared by The Lewin Group and the National Association of Health Data Organizations.

Participants at this meeting included representatives from the member organizations of the Consortium that were identified as key partners in the overall implementation of the education strategy. A list of participants appears in Appendix A. Lawrence Bartlett of Health Systems Research facilitated the meeting.

The first portion of the meeting focused on discussion of the Consortium's vision and mission. The bulk of the meeting was then devoted to the group discussing and providing guidance to the chairs of the new work groups concerning the types of issues they might address and activities they might productively pursue. The three work groups are:

- The Overcoming Barriers/Strategic Planning (OB/SP) Work Group, chaired by Delton Atkinson of the National Association of Public Health Statistics and Information Systems (NAPHSIS);

- The Web-based Resource Center (WRC) Work Group, chaired by Tom Doremus of the Public Health Foundation (PHF); and

- The Securing Funding (SF) Work Group, chaired by Elliot Stone of the Massachusetts Health Data Consortium (MHDC).

The meeting concluded with a brief overarching discussion of strategies for involving partners in the work groups. The agenda for the meeting is presented in Appendix B. A summary of the meeting's deliberations is presented below.

B.   Achieving Consensus on the PHDSC's Vision and Mission

To provide a context for the discussion of work group activities, as well as other Consortium efforts, the group first sought to clarify members' views concerning the Consortium's overall vision and mission. As reflected in the agenda, the group's discussion focused on addressing the following questions:

- How much of the Consortium's focus should be on Health Insurance Portability and Accountability Act (HIPAA) standards and implementation versus a broader data standards perspective for public health and health services research?

- Can the Consortium agree on a phased approach, with a very broad vision encompassing standards for public health, in addition to a strong, short-term focus on HIPAA standards and implementation?

- Should the Consortium's short-term educational efforts be primarily HIPAA-driven?

- Should the Consortium develop partnerships with standards organizations e.g., Accredited Standards Committee (ASC) X12, Health Level Seven (HL7), National Uniform Billing Committee (NUBC), National Uniform Claim Committee (NUCC) for developing the broader vision of data standards (e.g., vital statistics)? If so, how would the Consortium facilitate this collaboration?

1.   A singular focus on HIPAA versus a broader data standards perspective

Participants were in general agreement that, while HIPAA has been the catalyst for bringing this group together, the need for data standards for public health and health services research purposes has been and continues to be much broader than what HIPAA encompasses. The most important accomplishment of the Consortium has been to bring together groups from different segments of the public health and health services research communities to seek consensus on national standards. Therefore, as the Consortium continues its work, it needs to look more broadly, beyond HIPAA, to explore how different parts of the public health community can communicate on the full range of data standards.

Several participants made the point that defining the Consortium's scope to encompass the broad array of data standardization issues may encourage a greater number of State and local agencies to focus on and seek to better understand HIPAA. In fact, if HIPAA is not set in this broader context of data standards development, some of these agencies may conclude that it is not relevant to them. The group noted that the perspective of State health departments is important because they are inundated with many different requirements coming not only out of HIPAA but also from individual Federal agencies (e.g., National Electronic Disease and Surveillance System, NEDSS, from the Centers for Disease Control and Prevention). The Consortium should keep its focus on what decisions State health officers need to make for standards to work for their agencies. It is also important to describe how HIPAA requirements are going to be relevant to other data standards.

2.   Phased implementation efforts

There also was broad support for adopting a multi-layered and multi-phased approach to the Consortium's educational activities. They reiterated that it is not about making an "either-or" decision with respect to a focus on HIPAA or the broader data standardization perspective, but rather developing multi-level messages with a more immediate HIPAA emphasis placed within a broader data standards context. They suggested that the key question the Consortium needs to consider, as a voluntary group with limited resources, is where to focus its efforts.

In this context, participants recommended that the Consortium develop an overview educational piece on HIPAA, providing information about the standards and highlighting why HIPAA is important to public health officials and providing concrete examples of its relevance to public health. The Consortium should provide referrals through Web links to its member organizations and to standards organizations: the former are responsible for the more specific and detailed "How do I implement HIPAA?" educational needs of their constituents. Related to this, it was suggested that, in the short-term, the Consortium should encourage all member organizations to have a HIPAA component in all their events, web sites etc.

Participants further noted that the Consortium is a unique group in that it represents a broad base of public health and health services research organizations that have come together around the

issue of data standards. While some member groups are more directly involved in the use of HIPAA data than others, as a group the Consortium is in an ideal position to model public health interactions among the different data sets used by different organizations. In general, there was support for pursuing a modeling activity as a focused project, possibly within the Overcoming Barriers/Strategic Planning Work Group.

3.   Short-term educational efforts

While there was general agreement that it was appropriate for the Consortium to focus its short-term educational efforts on HIPAA-related issues, participants considered it important to be clear about the extent to which the Consortium should be expected to help the constituents of its member organizations on how to "get started" when implementing HIPAA. The general feeling was that the Consortium does not have the resources to provide that type of support and therefore the Consortium should not seek to posture itself as doing so. To the extent that they are able, individual Consortium member organizations would continue to be responsible for providing this support to their constituencies. One participant articulated a difference between acting as an educational resource or as a hands-on technical assistance body. While the Consortium may not have the resources to provide technical assistance, an overarching educational function would be very important for various players in the public health systems.

It was noted that the Consortium represents some very powerful groups in public health and health services research, which together have a significant influence in: (a) making State and local policymakers and researchers aware of the importance of data standards development and the potential impact it can have on their activities; (b) providing basic information and linkages to information about data standards development activities; and (c) encouraging those constituents' involvement in or input into these standard development activities.   If data standards are to be made a priority there also has to be clear evidence showing policymakers the value of dedicating resources to this issue in their respective States. Participants felt the Consortium could best fill this role. They also noted that the Consortium could be a strong voice in educating about HIPAA in dialogues with standards organizations (e.g., NUCC, NUBC, HL7, ASC X12).

4.   Partnerships with other standards organizations

With respect to the question of whether the Consortium should establish partnerships with other standards organizations (e.g., ASC X12, HL7, NUBC, and NUCC) to develop a broader vision of data standards, participants pointed out that the Consortium already has broad partnerships with these standards organizations. However, they noted that it would be difficult to forge a broader, shared vision with these standards organizations without a specific model in mind as previously discussed. They suggested that a key question requiring further discussion was whether the most effective strategy would be for the Consortium to develop this broader model and take it to these organizations, or seek to jointly develop a model with them.

C.   Guidance to the Overcoming Barriers/Strategic Planning Work Group

With the previous discussion of the Consortium's vision and mission as context, the group proceeded to discuss the charges given to several new Consortium work groups and to offer guidance to each of these work groups about priority issues to address and activities they might include in their work group action plans.

The discussion began with the newly established Overcoming Barriers/Strategic Planning (OB/SP) Work Group, chaired by Delton Atkinson. This group is charged with developing strategies to overcome barriers to migrating to national standards by leveraging the HIPAA standards more broadly for public health and by working more effectively with the private sector.

Prior to the meeting, Suzie Burke-Bebee of the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC) prepared and circulated for comment a matrix summarizing the major barriers to implementation and strategies for overcoming them that were identified in the Education Strategy report. A total of 22 barriers and 13 strategies were identified from the report and included in this matrix (see Appendix C).

Given the significant number of barriers identified and the limited resources to address them, participants sought to give guidance to the Work Group by identifying what they considered to

be the most important barriers to be addressed. In some cases, several barriers identified in the report were considered loosely related to one another and were therefore grouped together. The most important barriers identified by the group, in priority order, were the following (Note: the numbers reference the sequence in which these barriers are listed in the matrix found in Appendix C):

- The lack of clear mandate for public health and health services research (#1) and a lack of unified national leadership (#11).

- Many State and local agencies and other affected constituencies not knowing where/how to start (#16) and having differing levels of readiness (#4).

- Federal and State politics and fragmented, categorical funding, programs, and data collection efforts (#3).

- The need for States, localities, and/or programs to change from current systems to broader initiatives, and lack of coordination across multiple data standards and integration of efforts (#6).

- The lack of funding for Consortium activities (#2).

- Staff and organizational resistance to change (#21).

Given these priority barriers, participants then brainstormed about potential strategies for overcoming them. Participants felt that the lack of unified leadership in the standards development process was the biggest barrier, and several noted that it actually related to all the other barriers outlined in the matrix. There was a discussion about the Consortium's potential to provide this unified national leadership role, and agreement that the Consortium could and should do this. To overcome the barrier of lack of national leadership on data standards issues, the following strategies were put forth:

- Develop a set of guiding questions that each Consortium member organization will be asked to address in its own educational activities. Questions could include: What is this agency doing to show how its activities relate to HIPAA or, more generally, data standards? What is this agency doing to adopt data standards in its future agenda?

- Use the Web-based Resource Center as a dissemination tool for the Consortium to show that there is a clear mandate and national leadership for data standards.

■   Designate leads on HIPAA and data standards within Federal and State agencies.

A goal of the OB/SP Work Group would be to articulate a unified vision to which all the different players affected by data standards could relate.

There was also extensive discussion surrounding the issue of diversity and fragmentation of public health data functions at the State and local levels, which participants noted was reflected by the diversity of groups represented around the table (e.g., statistics, epidemiology, research, health care delivery). Recognizing that the key message that needs to come out of the Consortium is that data standards are a unifying and integrating factor, participants offered the following strategies for addressing data fragmentation:

■   Offer the National Governors' Association and the National Council for State Legislatures the opportunity to participate in the Consortium, in order to educate these groups on data standards and ensure that data fragmentation at the State level becomes one of their priorities.

■   In order to make efforts to address data fragmentation a priority, develop "best practice" or "use-case scenarios" to illustrate how joining data from different partners (including the private sector) has resulted in a unique ability to solve problems in the past, also focusing on problems that have been caused by data incompatibility.

■   Link data fragmentation initiatives to States' e-government initiatives.

To address the barrier of differing levels of readiness and lack of coordination between and within States in developing and implementing systems, participants offered the following strategy:

■   Develop concrete "best practice" models for how to use the data that will result from greater standardization — specifically, models for translating standards to the local level or models for linking claims, administrative, and surveillance data at the State or local level. These models should be developed by the OB/SP Work Group and disseminated through the Web-based Resource Center Work Group.

Several participants felt that the barrier identified in the matrix (#2) as "lack of funding for

standards development" was not really a barrier. They noted that funding is available but is not organized or leveraged in appropriate ways to meet the needs of the public health constituencies. The real barrier lies in convincing the public health community, which traditionally does not seek to partner with the private sector, for example, to begin looking at cooperative efforts.

Finally, it was noted that another barrier outlined in the matrix (#7) — "the difficulty of convincing States and programs not to go it alone" — was not really a major barrier to this effort. Participants felt that States do not want to go it alone, and this barrier could be eliminated if appropriate educational resources are made available to them.

At the conclusion of the discussion about the OB/SP Work Group, participants were asked to indicate if they or another member of their organization would be interested in participating in this Work Group. The following individuals expressed their interest:

- <   Jessica Townsend, Health Resources and Services Administration (HRSA)
- <   Jeffrey Koshel, Health Resources and Services Administration (HRSA)
- <   Denise Love, National Association of Health Data Organizations (NAHDO)
- <   Helen Regnery, Association of Public Health Laboratories (APHL)
- <   Rachel Block, Centers for Medicare and Medicaid Services (CMS)
- <   Jerry Gibson, Council of State and Territorial Epidemiologists (CSTE)
- <   Anjum Hajat, National Association of County and City Health Officials (NACCHO)

In addition to these volunteers, the following individuals and organizations had expressed an interest in participating in this Work Group prior to the meeting: Michael Fraser, HRSA; Jason Goldwater, CMS; Marjorie Greenberg, CDC/NCHS; Yoku Shaw-Taylor, Public Health Foundation (PHF); Walter Suarez, Minnesota Health Data Institute (MHDI); and representatives from the Association of Maternal and Child Health Programs (AMCHP), Association of State and Territorial Health Officials (ASTHO), and National Association of Local Boards of Health (NALBOH).

D.   Guidance to the Web-based Resource Center Work Group

The Consortium's education strategy described a Web-based resource center of standards development activities that would include tracking information about implementation efforts related to data standards and integration across States or programs. The mission of the Web-based Resource Center (WRC) Work Group, chaired by Tom Doremus of the Public Health Foundation, will be to track and disseminate on an ongoing basis the efforts related to standards implementation and data integration.

There was general agreement among participants that the short-range goals of the WRC Work Group should focus on HIPAA education and implementation issues (e.g., Health Care Services Data Reporting - HCSDR - Implementation Guide). In that regard, the following strategies were suggested:

■   Develop Web-based educational materials for helping public health data users determine if the HCSDR Implementation Guide is relevant to their programs, and if so, how to begin the process of implementing the standards by using the guide within their programs.

■   Develop partnerships with regional organizations leveraging their HIPAA efforts to help with the implementation of the HCSDR Implementation Guide. A Consortium member representing the National Association of County and City Health Officials (NACCHO) indicated that her group is working to develop a Web-based clearinghouse and would like to partner with the WRC Work Group to ensure that local issues are addressed and to avoid duplication of work efforts.

■   Collaborate with standards organizations and Consortium members to leverage their HIPAA data standards' educational materials. One participant emphasized, that the Consortium's collaboration with regional efforts should not be limited to implementation of the HCSDR Implementation Guide. For example, it was noted that the Workgroup for Electronic Data Interchange (WEDI) Strategic National Implementation Process (SNIP) contains some useful documents the WRC could use for URL linkage. Therefore, the role of the WRC Work Group could be to provide an overview for the importance of standards and, when linking to other standards efforts, to clearly identify how this affects public health professionals (e.g., "white papers").

The following specific strategies for the content and design of the WRC web site were offered:

- Develop and maintain a Web-accessible list of existing data standards and standards development activities, providing their context and identifying their relevance to public health.

- Design the web site using a role-based approach with a search engine to drill-down through short interactive questions. The role-query process would first direct users to an appropriate Web-page based on who they are and what information they want. Once there, the search engine-query would then provide a list of possible "hits" to the relevant documents requested (with their URLs) based on content (like Yahoo or Google). Participants were largely in favor of an interactive site with online surveys where users could provide input (particularly for users at the local level to have input into standards development), but noted that this would require full-time staff. Instead, they opted for a frequently asked questions page to define the site's content.

At the close of the discussion, the following indicated an interest in either participating or having a representative from their organization participate in the WRC Work Group:

- Helen Regnery, Association of Public Health Laboratories (APHL)
- Rachel Block, Centers for Medicare and Medicaid Services (CMS)
- Anjum Hajat, National Association of County and City Health Officials (NACCHO)
- Alana Knudson-Buresh, Association of State and Territorial Health Officials (ASTHO)
- Bob Davis, New York Statewide Planning and Research Cooperative System (SPARCS)
- Virginia Van Horne, Academy for Health Services Research and Health Policy (AHSRHP)
- Pam Akison, National Association for Public Health Statistics and Information Systems (NAPHSIS)

These Work Group members are in addition to the individuals and organizations who had volunteered to join the Work Group prior to the meeting: Suzie Burke-Bebee, CDC/NCHS; Vicki Horner, Washington State Department of Health; Hetty Khan, CDC/NCHS; Denise Love, NAHDO; Walter Suarez, MHDI; and Michelle Williamson, CDC/NCHS.

E.   Guidance to the Securing Funding Work Group

The Consortium's education strategy report recommended that the Consortium undertake a concentrated effort to secure funding for its activities in order to be able to carry out its mission. The mission of the Securing Funding (SF) Work Group, chaired by Elliot Stone, will be to identify high-priority Consortium activities requiring funding, explore potential funding sources, and explore partnerships.

Participants identified the following high priority projects and efforts for which to assure continued funding or obtain new funding:

- NCHS's "core coordination" role for the Consortium;

- Web-based Resource Center;

- Health Care Services Data Reporting Implementation Guide;

- Modeling efforts for Public Health standards development;

- Support of State and local HIPAA implementation efforts; and

- Other educational activities and products.

Participants also discussed potential new sources of funding and how the SF Work Group can go about securing funds for other work groups' activities. Among their suggestions:

- Foundations;

- Government agencies ("in kind" support, as well as grants/contracts);

- Consortium member organizations ("in kind" contribution and possible Consortium membership dues); and

- Private companies.

The priority activity highlighted for the SF Work Group was to play a major role along with the OB/SP Work Group in developing a business plan for the Consortium that facilitates its ability to garner additional funding for projects. It was noted that NCHS might be able to provide a small professional services grant to a contractor to develop a business plan. Marjorie Greenberg reiterated NCHS' commitment to continuing its core coordination role for the Consortium.

Participants raised the point that since the Consortium is not a legal entity, or 501(c)(3), it is not eligible to receive foundation funding. However, since there was no strong push for the Consortium to undergo a legal or structural change at the present time, it was suggested that the Consortium's member organizations should apply for grants on its behalf. Participants thought the Consortium should go further and actually designate a member organization that is itself a 501(c)(3) to formally take the lead on applying for grants. Denise Love of NAHDO indicated definite interest and Jerry Gibson of the Council of State and Territorial Epidemiologists (CSTE) indicated possible interest on behalf of their organizations in filling this role. Another approach suggested was that the organizational partners of the Consortium (e.g., ASTHO, CSTE, NACCHO, NAPHSIS, and NAHDO) might apply as a coalition or "mini-consortium" for grants on behalf of the Consortium.

It was decided that in the short term, the Consortium needs to identify and pursue their immediate activities and projects through a foundation grant. Denise Love of NAHDO volunteered to draft a grant proposal for the WRC with initial seed money provided by NCHS. NCHS also indicated that it might be able to provide seed money to individual organizations to support development of other priority proposals such as educational materials for the HCSDR Implementation Guide. Participants identified the need to implement a formal process for soliciting, reviewing, and prioritizing project ideas and determining which entities will take the lead on each project.

In the long term, participants agreed that the Consortium's work is too important to continue to rely on volunteers, and so its efforts should be most concentrated on developing a business plan. For the time being, participants were in agreement that NCHS has the valuable staff, resources, and funds to continue its role as coordinator of the Consortium.

The following individuals indicated interest in participating in the SF Work Group:

- <   Roxanne Andrews, Agency for Healthcare Research and Quality (AHRQ)
- <   Helen Regnery, Association of Public Health Laboratories (APHL)
- <   Anjum Hajat, National Association of County and City Health Officials (NACCHO)

These individuals would join Suzie Burke-Bebee from CDC/NCHS; Denise Love from NAHDO; or a representative from NAHDO; and NAPHSIS, who volunteered to participate in the Work Group prior to the meeting.

F.   Discussion of How to Involve Partners in Work Groups

The solicitations made during the previous discussions for members to serve on the three new work groups were well received. During the final segment of the meeting participants discussed how their organizations could further assist in recruiting individuals to participate in Consortium activities, such as the work groups, that are vital to carrying out the Consortium's mission and vision. The members reaffirmed their commitment to the Consortium, however they acknowledged current resource limitations and the need to publicize and market for additional support in Consortium activities.
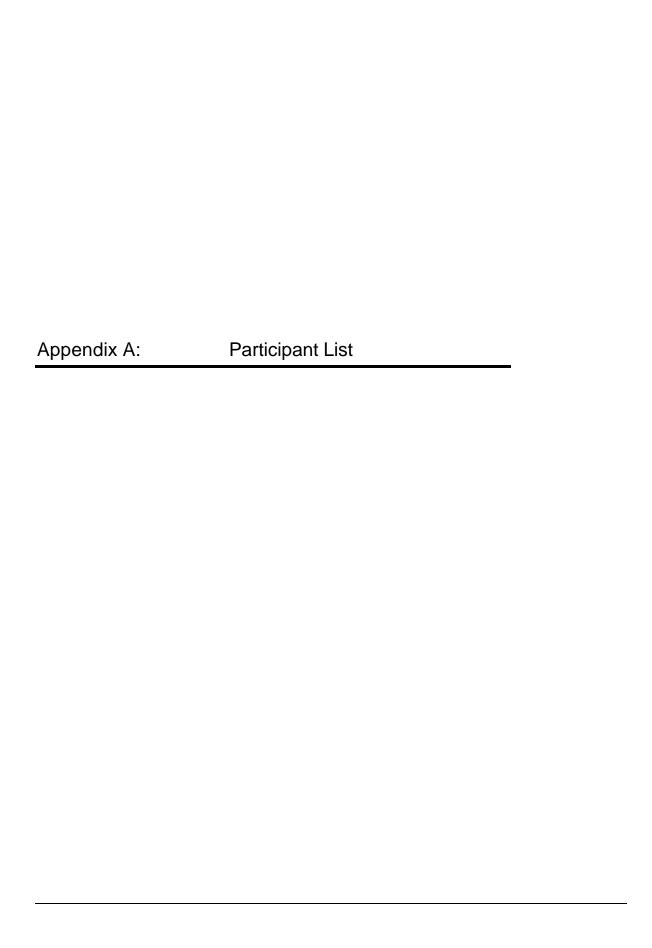
To raise awareness about the Consortium's activities, several participants suggested the following strategies:

- ■   Publish journal articles, focusing on Consortium activities and accomplishments, starting with the work efforts of the HCSDR Work Group and their HCSDR Implementation Guide.

- ■   Contact the *Journal of Public Health Practice and Management* about dedicating an issue on data standards that would reach a broad audience of public health practitioners.

- ■   Issue periodic press releases to highlight the Consortium's activities in specialized media, targeted to public health professionals.

There was a general sense that in order to recruit more active participants for work group activities, the Consortium needs to establish more specific, concrete projects. It was noted that the HCSDR Guide Work Group has the longest list of participants because its product is very concrete and relevant to the needs of the member organizations and the public health and health services research communities.

G.   Closing Comments and Next Steps

The consensus of the participants was that this was a very productive meeting and that considerable guidance was provided to the new work groups that would help shape the development of their action plans. In terms of immediate next steps, a short summary of the day's discussions will be prepared for the electronic AHSRHP newsletter. Consortium members will use that summary to publicize the Consortium and solicit interest from their respective organizations. It was also stated that a more complete meeting summary would be prepared for dissemination to the group in the next few weeks.

Appendix A: Participant List

Appendix B: Agenda

Appendix C: Matrix