

PUBLIC HEALTH DATA STANDARDS CONSORTIUM  
EXECUTIVE GROUP

MON., AUGUST 26, 2002  
11:00 A.M. - 1:00 P.M. EASTERN

**Walter Suarez, M.D.**, Executive Director  
Minnesota Health Data Institute (MHDl)

**Tom Doremus**, Information and Communications Specialist  
Public Health Foundation (PHF)

**Suzie Burke-Bebbee**, Health Informatics Specialist  
Centers for Disease Control and Prevention (CDC)  
National Center for Health Statistics (NCHS)

**Marjorie Greenberg**, Chief  
Data Policy and Standards Staff  
Centers for Disease Control and Prevention (CDC)  
National Center for Health Statistics (NCHS)

**Hetty Khan**, Health Informatics Specialist  
Centers for Disease Control and Prevention (CDC)

**Denise Love**, Executive Director  
National Association of Health Data Organizations (NAHDO)

**J. Arturo Coto, MD, MPH**  
Disease Surveillance Coordinator  
Nebraska Health & Human Services System  
Chair: External Cause-of-Injury (E-Codes) Work Group

**Susan Elder, MA**  
Director, Section of Health Statistics  
Center for Health Information Management and Evaluation  
Missouri Department of Health  
Co-Chair: Payer Type Work Group

**Michelle Williamson, BS, BSN, RN**  
Health Informatics Specialist  
CDC/NCHS

**Agenda:**

**Review description of Executive Group. Available at:**  
<http://www.cdc.gov/nchs/otheract/phdsc/execgroup.htm>

The Executive Group had an opportunity to review the description of the duties of the Executive Group. A question was asked whether the Executive Group was responsible for ensuring budgetary resources or whether that was the responsibility of the secretariat or the Business Development and Marketing Workgroup. The Executive Group is more of a policy making group, but would perhaps become the Executive Committee of the 501(c)3 corporation. It is possible that the officers of the Board of Directors will create a different executive committee. The Board may be a larger group and the executive committee a smaller working group named by the Board that can make decisions between regular meetings of the board. This Executive Group may function as a transitional group, but will be very important until a new arrangement can be reached. The Executive Group also needs to select a chair or co-chairs to head this committee. The workgroup suggests that there may need to be a better definition of the chair responsibilities so that people in the Consortium can better understand the time they will need to commit, relationships they will form or need to form, and the other associated conference calls and committees they will need to attend. Putting such a definition out on the PHDSC web site would fit with our principles of standardization. With many significant changes taking place in the next year, this will be a very interesting and challenging year for the Consortium.

**NCHS Update on FY 2002 contracts for Consortium projects – Suzie Burke-Bebee and Michelle Williamson**

Members of the NCHS reported on the contracts and projects currently underway:

1. Web Based Resource Center (WRC) – The WRC was formed on a recommendation from the education strategy, as a place for the audience to go as an education website. The NCHS is funding the bulk of this project. The contract has been returned from the Lewin group and their subcontractor, Social and Scientific Systems Inc. This contractor will be responsible for the technical aspects of the Web Based Resource Center. The dollar amount remains the same however we are still looking at some of the tasks. Some of the tasks defined in the entire project were more costly than could be funded originally, so the contract was divided into two parts. NCHS is currently pursuing other sources for funding the second part of the contract. The second part will be the same contractor but the tasks will enhance the first contract. The WRCWG has been designing the web center and has helped develop the contract. They will serve as an advisor mechanism to this contractor. Tom Doremus has resigned his position as chair of this committee, which could compromise the effectiveness of this committee. Tom and Bob are working on wording to advertise the job. The Steering committee will be targeted first. Tom estimates that the time commitment for this job could be 10 hours per

week. The tasks involve evaluating the materials that come to the committee, staying in communication with other workgroup members, and communicating with the NCHS staff. This position needs to be targeted to someone who has a job that will be benefited by the WRC. There are several other leadership positions in the Consortium that are in transition at this time. Ted applied for the domain name for the WRC, but since he is leaving the National Boards of Health, someone else will need to support the domain name. Bill Yasnoff, in his position, will be promoting the NHII activities and helping to secure additional funding for this function. Members of the Consortium need to be able to support the Consortium if it is to continue.

2. Michelle reported on the contract with NAHDO to create the health care services reporting guide. Included in this contract are a gap analysis and several white papers. The gap analysis is related to a crosswalk between the UB-92 and necessary data elements for data reporting. The white papers will detail the processes that New York used to establish the reporting guide, implement the reporting guide, and create a win-win scenario for Public Health. The preliminary work is being done to have these data elements accepted into USHIK.
3. NCHS has established and funded a contract with Sally Klein for documentation of conference calls for all of the Consortium workgroups for the next year.
4. NCHS has contracted for the 2003 steering committee meeting.

These contracts have been supported by NCHS funding plus \$30,000 from ASPE for the past two years. Additionally, the NCHS is pursuing funding for the second contract for the WRC. This could potentially be funded with FY 2003 money. It is very positive that these projects are moving forward. Thanks to the staff who have developed the statements of work to create these contracts.

**Discuss status of requests to potential organizations interested in funding or supporting the application process for a 501 (c) 3 corporation. – Elliot Stone and Walter Suarez**

Discussion occurred at the 2002 Steering Committee meeting that the Consortium should move forward with establishing itself as a 501(c)3 corporation. A letter was sent to some members of the consortium, ASTHO, NAHDO, JHSPH, to see if they were interested in providing some support. Additionally, a letter was to be sent to members of the Executive Group to solicit membership for the founding Board of Directors. Members were to proceed with communications within their organizations to determine if contributions could be secured to fund the establishment of the non-profit corporation. If there was not enough support to move forward, then the members were to solicit support from

their organization to be an entity that would facilitate establishment of this new organization within the member organization. This short-term approach to “incubate” this new organization would still allow the Consortium to engage in activities that cannot be pursued because we are currently not separate from a Government entity and cannot apply for grants. Under the “incubation” strategy, the Consortium might prepare itself to spin off as a non-profit corporation by hiring a part time director. Under either of the strategies, the Consortium needs to proceed with identification of individuals who will become the Board of the new entity. Then the Board will need to move forward with identifying committees, etc. The letters have gone out to determine interest in establishing the corporation, but the letters regarding Board membership have not gone out.

Marjorie reported that she had had a conversation with Alana Knudson-Buresh, from ASTHO but who has now moved to NAHDO. Alana suggested that Murray Sagsveen from North Dakota could possibly provide some legal assistance to move to a 501(c)3 corporation. NAHDO has also considered assisting with development of the corporation, but the issue has not been taken to their board yet.

Marjorie also reported that David Ross has expressed interest in serving as an “incubator” of the Consortium. He has suggested that this might be a prudent course to consider before moving forward as a legal entity. The incubating organization could take on some of the operating functions and could engage a person who could move the Consortium step by step into its own organization. Dave has received a \$3 million grant from RWJ to establish a Public Health Informatics Institute. That grant could potentially increase to \$30 million next year. The purpose of the grant is to work with health care providers to help them become familiar with informatics. The institute will evaluate vendors, promote informatics in public health departments and implement many of the things the Consortium has been promoting. Their stated mission is not to develop standards, but to work with standards that are already developed so they can be used in public health—particularly in response to bioterrorism. Dave does not feel these two organizations should be in competition, but rather work toward the same goals. Dave is also planning to work with an organization of State CIOs in public health departments. Again, the goal is to incubate them and then spin them off later. While the Consortium is much further along than the CIO group, the Consortium does not have a stand-alone organization with membership dues and therefore is not self-supporting. Dave is checking with RWJ to determine if they would support this arrangement with the grant funding.

The discussion continued regarding the incorporation process. Members felt it might be good for the Consortium to move forward, and away from NCHS, although continued funding would be necessary for a while. CDC would also consider providing some funding, but cannot do so to the NCHS entity. Another alternative is that the Consortium could become a “project” of an existing 501(c)3 corporation. This arrangement could be a short or long-term solution, but would

allow the Consortium to seek funding under the umbrella of the parent organization. While the establishment of the 501(c)3 status could occur in a few months, the IRS would not recognize the entity for several years. The organization would become a non-profit in any state and could operate as a non-profit under a preliminary status. Ultimately, the IRS will determine the final status and assign the 501(c)(X). The Consortium would need a business plan and a part time executive director in order to move forward with anything but a shell. Some funding from Dave Ross or RWJ might be used to move this organization forward, provide communication avenues, establish newsletters, etc. There could also be some collaboration with the CIO group or they could be encouraged to become members of the Consortium. Some members of the Executive Group feel that we should move carefully and not wash away the efforts of the Consortium in a bigger machine. What makes the Consortium work is the commitment to understand the process and support data elements. Denise mentioned that NAHDO has been approached by several top-drawer persons to work on specific projects. We could move aggressively to establish the 501(c)3 right now and get some person to take us to the next steps. There is concern that the incubation strategy might be perceived as absorption by that organization while charging out of the gate—even part time—might make sense. There is also concern that as a non-profit, we might not have the funding to engage a leader of the group. As we move continuously toward the 501(c)3, we will need a leader that is not assigned to this as just another duty. The speed that we proceed depends on the time of the leader, but if we jump too soon, we may not have funding for even 10 hours of a leader and that may stall all of the activities. We have projected costs for establishing the legal structure and a part time director, but it is difficult to project a business plan because we don't know which projects to move forward into an organization that does not have a structure in place. We must also consider the need to develop indirect rates, business products, etc. which will take a proposal writer, a grant writer, etc. This process will make or break, depending on who is the incubator. We could move forward with great assistance or lose our momentum. Many Consortium members have been unable to pay membership dues or fund their own attendance at the annual meeting. While projects may be a far better source of funding, we may need to consider membership dues until projects can get off the ground. The transitional time is very important. The Consortium needs to develop a description on paper of the host organization/Consortium arrangement so we could make visits to negotiate the details. This paper should describe the functions of the executive director as it pertains to the organization moving forward towards independence. The Consortium has developed something unique and could continue, but the BDM group does feel that we could gain from incorporating. Elliot and Walter will meet to develop a draft of this type of document and the BDM needs to have a follow-up call to consider all of the options at this critical time.

**Discuss possibility of PHDSC functioning as a “project” of an existing 501 (c) 3 organization, either short-term or long-term – Elliot Stone**

Elliot was not available for this call.

**New Consortium Work Groups (NHII and Privacy) – Marjorie Greenberg and Michelle Williamson (document attached: NHII WG)**

Several new workgroups were suggested at the steering committee meeting in March. In light of the loss of leadership from some existing workgroups it is difficult to think about new workgroups. The OBSP was very new, and its charter seemed to be compatible with the NHII, so it has been suggested that these two workgroups be combined. The list of volunteers disappeared after the Steering Committee, but the mission of this new group seems to blend with several other Consortium activities. This group, however, could take a great deal of time. It is necessary for such a workgroup to develop short-term goals so that people would have an idea of what the group is moving toward. It may also help people to identify individuals who could participate in short term projects. Much of the work of this group could also be part of the educational component of the WRC. As the WRC evolves, the on-line conferencing will begin to develop a focus. Until that is functioning, it is more difficult to link individuals and resources and it is harder for funding sources to understand how people are engaged to develop goals. The focus for the coming year is the WRC, and the capacity for the on-line conferencing is in the second contract. It may be enough for the Consortium to concentrate on the WRC, the reporting guide, and the BDM group. The data elements from the e-code workgroup are now finding their way into the UB and the reporting guide. NAHDO is setting up a web-based clearinghouse for ED data, and that may come together fairly quickly. The necessity for ED data and patient safety data will not go away, but how e codes are addressed will evolve. At this time, no one is doing outpatient data collection, so that is a frontier.

Privacy is another workgroup proposed at the Steering Committee. While every state has named a privacy officer, these individuals are at a 25 thousand foot level while the work level is more fundamental. Every workgroup will need a champion to incorporate the workgroup activities with their regular job, but we don't want to spread ourselves too thin. The main function of the Executive Director will be to keep a focus so that workgroups can form and de-form as the need arises.

**Draft agenda for 2003 Steering Committee meeting – Hetty Khan (document attached: Consortium draft agenda1 8.16.02)**

There will be a conference call of the entire Steering Committee in three weeks. Some of the discussions of today will be on that committee call. The annual Steering Committee meeting is scheduled for March 12 and 13. The agenda has been established based on evaluations from the last meeting. Those evaluations

have suggested that we need to allow enough time for presentations and Consortium business. We are also hoping to have a balance for workgroup activities, discussion, and contract activities. The suggestion is to have the meeting center around three topics: 1) current workgroup activities and the status of those; 2) the status of the organization, using an open, facilitated discussion on that topic; and 3) Consortium business and plans for future projects. We could focus ½ day on each of these topics, have fewer presentations, and allow time for discussion about how the Consortium can help individual members with their business and what the Consortium should be doing. Some reports and updates could be condensed and HIPAA presentations could be brief since we will be very close to implementation. Consortium business should be part of every day, not left until the end. It was suggested that the meeting should only be one day long to cut back on travel expenses, however travel arrangements often mean that people will leave early on the first day. Although this suggestion will be considered, Marjorie would like the meeting to remain at 1½ days. To streamline the meeting, however, reports could be put into concise bulleted format and sent out early. Tom will also develop a brief survey to ask people what they want to get from reports and what they want to get from the Consortium. This hard data could be used as a base for funders. These suggestions will be discussed at the steering committee conference call.

### **Agenda for Steering Committee conference call – September 17**

This will be developed in draft and sent to the committee before the call.

### **Selection of Executive Group Chair**

The process for selecting an Executive Group Chair will be to develop a short job description of the position and send an e-mail to members requesting nominations. NCHS staff will develop a form so that people can see a list of the members of the group and submit nominations by checking boxes.

### **Other topics**

Discussion of the comments received in the open forum for the reporting guide. The guide has received 110 comments, which are mostly typos. It would be good if states would give this a closer look, but the September 28 deadline would not give them much time. So far the Consortium, as author of this guide, has been comfortable with the comments.

### **Action Items:**

- Advertise the WRC Chair position – Tom and Bob
- Write definition of Executive Group Chair and send out names – NCHS
- Find someone (entity) to support the web domain – All Exec Group members

- Send out letters to Exec Group soliciting potential Board membership – Walter and Elliot
- Continue dialogue with NAHDO regarding assisting the Consortium – Denise
- Continue discussions with Dave Ross – Marjorie
- Consider requesting/requiring membership dues – Steering Committee
- Develop and write a description of the parent organization/Consortium arrangement – Elliot and Walter with BDMWG
- Seriously consider the pros and cons of developing new committees such as the NHII and Privacy – Steering committee
- Develop a survey on what Steering Committee members want from reports and the Consortium – Tom
- Develop and send the agenda for the Steering Committee conference call – NCHS staff

## **Adjourn**

### **Job Description for the Executive Group Chair**

The Public Health Data Standards Consortium Executive Group Chair will:

- Coordinate and direct the activities of the Executive Group
- Serve as the focal point of the Executive Group for the Secretariat and all Executive Group members
- Work in conjunction with the Secretariat to plan the agenda and conduct two hour quarterly conference calls with the Executive Group
- Work in conjunction with the Secretariat to plan the agenda and conduct an annual two hour conference call with the Steering Committee

Report the Executive Group activities to the Steering Committee members through email, conference calls and annual meetings

### **Executive Group Members**

#### **Amy Bernstein, ScD**

Director, Development and Analysis Group  
Centers for Disease Control and Prevention (CDC)  
National Center for Health Statistics (NCHS)  
Co-Chair: Payer Type Work Group

**J. Arturo Coto, MD, MPH**

Disease Surveillance Coordinator  
Nebraska Health & Human Services System  
Chair: External Cause-of-Injury (E-Codes) Work Group

**Robert Davis, MS, Director**

SPARCS, New York Department of Health  
National Uniform Billing Committee (NUBC) State Representative  
Chair: Health Care Service Data Reporting Guide Work Group  
Co-Chair: Education Work Group

**Susan Elder, MA**

Director, Section of Health Statistics  
Center for Health Information Management and Evaluation  
Missouri Department of Health  
Co-Chair: Payer Type Work Group

**Marjorie Greenberg, MA, Chief**

Data Policy and Standards Staff  
Centers for Disease Control and Prevention (CDC)  
National Center for Health Statistics (NCHS)  
National Uniform Billing Committee (NUBC) Federal Representative

**Denise Love, MBA**

Executive Director  
National Association of Health Data Organizations (NAHDO)

**Steve Steindel, Ph.D.**

Supervisory Health Scientist  
Centers for Disease Control and Prevention (CDC)  
National Uniform Claim Committee (NUCC) Federal Representative

**Elliot Stone, M.U.A.**

Executive Director, CEO  
Massachusetts Health Data Consortium (MHDC)  
Co-Chair: Business Development & Marketing WG

**Walter Suarez, MD, MPH**

Executive Director  
Minnesota Health Data Institute (MHDI)  
Co-Chair: Business Development & Marketing WG and Education WG  
National Uniform Claim Committee (NUCC) State Representative