



STEERING COMMITTEE CONFERENCE CALL AGENDA

TUESDAY, SEPTEMBER 17, 2002
10:00 A.M. - 12:00 P.M. EASTERN

Welcome and Introductions – Executive Group Chair

Tom Doremus, M.S.
Information and Communications Specialist
Public Health Foundation

Judy Parlato
Clinical Advisor, R.N., B.S.N., M.B.A.
MA Division of Healthcare Finance and Policy

Sally Klein, RN, MBA
Montana HIPAA Project Manager
National Association of State Medicaid Directors

Marjorie Greenberg, M.A.
Chief, Data Policy and Standards
NCHS

Walter Suarez, M.D., M.P.H.
Executive Director and CEO
Minnesota Health Data Institute

Claudia Tessier, CAE
Executive Director
Mobile Healthcare Alliance

Mary Smith, Ph.D.
Chief, Bureau of Evaluation and Services
Mental Health Statistics Improvement Program

Kathleen Cook, BSN, RN
Program Manager
National Association of County and City Health Officials

Starla Ledbetter, MHSA, RHIA
Assistant Manager, Patient Discharge Data
CA Office of Statewide Health Planning /Development

Jonathan Lawniczak
Director, Government Relations
Academy for Health Services Research and Health Policy

Katherine Kvale, M.D.
Epidemiologist
WI Division of Public Health

Elliot Stone, MUA
Executive Director and CEO
Massachusetts Health Data Consortium

**Robert Davis, M.S., Director
New York Statewide Planning and Research Cooperative System**

**Barbara Rudolph, Ph.D.
Scientist, University of Wisconsin
Center for Health Systems Research and Analysis**

**Suzie Burke-Bebbee, RN, M.S.
Health Informatics Specialist
NCHS**

**Hetty Kahn, RN, M.S.
Health Informatics Specialist
NCHS**

**Michelle Williamson, RN, B.S., B.S.N.
Health Informatics Specialist
NCHS**

**Amy Bernstein, Sc.D.
Director, Development and Analysis Group
NCHS**

**Janet Marchibroda
Chief Executive Officer
eHealth Initiative**

**Mike Sorrel, Ph.D.
Research Analyst
Wisconsin Bureau of Health Information**

**Sharon Sprenger, RHIA, M.P.A.
Project Director, Division of Research
JCAHO**

**Tim Stephens
Director, Education and Training
National Association for Public Health Statistics and Information Systems**

**Roxanne Andrews, PhD
Research Scientist
Agency for Health Research and Quality**

**Jerry O'Keefe
Director, Health Data Policy Group
MA Division of Healthcare Finance and Policy**

**Dave Lathrop
WA Dept Health**

**Jason Goldwater, M.A., M.P.A.
Program Analyst
CMS**

Deanna Caloggero

MA Health Data Consortium

Report on Executive Group Conference Call – Marjorie

The Executive Group was developed in response to the planning meeting and is composed of the chairs and co-chairs of all of the working groups. The first conference call was held in late August where the group approved the description of the duties of the Executive Group. It was determined that the group will be a policy making group and is in the process of naming a chair. The Executive Group has had discussions with the BDM group regarding the Consortium becoming a stand-alone organization. Additionally, the Executive Group has discussed the future of some of the workgroups that were proposed at the Steering Committee meeting last spring. There is much activity at a national level regarding the HIPAA rules, the liaison activities with NEDSS, the eHealth Initiative, and NCVHS hearings on privacy. While everyone is scurrying to implement the HIPAA rule, many State and Local health associations are feeling under-resourced to deal with the rule. Many are very concerned about privacy and need help understanding that necessary information can still be provided and such data collection is good for the nation. In addition, the OSBP workgroup is currently inactive but could be resumed as part of the NHII. While all of these potential workgroups serve a vital purpose, the Executive Group has decided not to establish these workgroups yet but to take the issue to the Steering Committee.

Several members expressed desire to work on the privacy committee. John has been working with AHRQ and Michael Fitzmaurice on three workshops this spring. Barb Rudolph and Carol Stocks are already working on these issues. Janet mentioned that EHI has three workgroups: data standards, privacy & security, and personal health. The privacy and security workgroup, chaired by Tom Hastings, would like some public health people to work on it or to partner with PHDSC. So many public health people seem to be swamped. The first meeting of this committee is scheduled for Sept 23 and 24 in Washington DC. Janet will send information to NCHS regarding these workgroups. If any one of these people would be willing to volunteer to chair the privacy workgroup, please contact Marjorie.

Several members also volunteered to be part of the NHII workgroup: Bob, Claudia, Kathy Cook, Starla, Jeanna (with APHL), Janet, Dave Lathrop, Elliot, and Roxanne, Barb, and perhaps someone from CSTE. John may attend some.

NCHS update on FY 2002 contracts for consortium Projects – Suzie and Michelle

Suzie reported that the contract with the Lewin Group went through last week. The original contract specifications were for about \$250,000, so that has been divided into two contracts. The basic contract has been funded, which includes web links, educational materials, and search engine. Bulletin boards and web conferencing will be included in the second contract. Educational materials planned include the introduction to the Consortium, tutorial 101 for the status of public health practices, public health informatics and public health data standards. This content will need analysis. The kick-off call for the WRC will be September 27. Interested members are invited to participate. Elliot volunteered Amanda Sullivan, and Lydia Massachusetts. Suzie will send out information about the call to the listserv. We are still looking for additional funding for the second part of the contract—essentially the last 1/3 of the costs. Members with ideas of how to obtain this final funding should contact Marjorie. The WRC may also contain the reporting guide from EHI as well as the 837 Reporting Guide from Bob. Additionally the site may carry a link to the NIH website which will be the official website for OCR regarding privacy. Our link will also provide information in the language that can be understood by researchers. Plans are to assure that this website will allow members to send money and have membership information.

Michelle reported on the contract with NAHDO to develop educational materials to support the reporting guide. These educational materials will be geared to State and Local health departments. NAHDO is collaborating with WRC to develop electronic educational materials and a comparison crosswalk from the guide to the UB-92. Three white papers will detail the impact of legislation on data collection, the implementation of the guide in New York, and the win-win situation created by using the guide to report administrative and clinical data to public health. The reporting guide is the first implementation guide to

include data object descriptors to enable eventual transition to XML. Ultimately, USHIK will carry the data elements.

AD Hoc Work groups Update

E-codes – The e codes workgroup has been active in making sure the UB-02 carries three dedicated spaces for e codes and that the reporting guide also carries these data elements.

Payer type – Amy reported that the WG presented a typology in 2001. The PLANID NPRM is expected out the first quarter of 2003. Suzie will send this information out as a reminder to everyone. The payer type workgroup plans to review this NPRM when it is published and submit comments on behalf of the Consortium.

Reporting Guide – Bob reported that the reporting guide has gone out for public comment. Responses have been written and some potential changes have been identified. The next step is a public information forum at the X12 meeting in Miami in October to justify the responses to the comments. Two types of comments have been received, those that request clarification of situations, and those that believe it should not be limited to institutional reporting. The workgroup is trying to establish a business case for inclusion of data elements for professional reporting. Version one, the institutional based guide could be published yet this year and approved by X12. After that the workgroup will begin a massive effort to educate people about how to use the guide. New Jersey will potentially be the first state to implement and New York plans to use the guide for current and ER data collections. New York will also be using the guide to associate cost data with surveillance activity—linking NEDSS with administration and correlating diagnosis with chief complaint. This work has been a major accomplishment for the Consortium and workgroup and will provide fodder for the NHII workgroup.

WRC – Tom reported the WRC has been blessed with an infusion of funding thanks to NCHS. This seed money will allow the Lewin group to develop the basics for the WRC and work toward the goals of education workgroup. The WRC would like all members of the Steering Committee to submit short biographies so that the WRC can use this information to obtain technical expertise when questions arise on data content for the WRC. These bios will also help the WRC to get a broad based view on issues from various jurisdictional levels. The WRC is also looking for a chair or co-chairs. Members may make recommendations to the workgroup or to NCHS.

BDM report on establishing non-profit – Elliot and Walter

The BDM has been actively engaged in efforts to have the Consortium become a separate legal entity. The group does recommend that we incorporate, and Elliot has developed a list of all the steps need to be taken to incorporate. The BDM has also sent letters to Steering Committee members to seek interest in funding the PHDSC if it becomes a separate entity or to assist with legal expertise or funding. Murray Sagsveen has offered, through ASTHO, to help with the legal work. Several other entities have expressed an interest in assisting with organizational structure or funding: 1) Dave Ross, with the Taskforce for Child Survival and Development; 2) John Steinwachs, Johns Hopkins School of Health; and 3) Janet Marchibroda from eHealth Initiative.

The BDM has identified four possible alternatives for the Consortium: 1) remain as it is and continue to function as a government entity; 2) establish itself in an “incubator” situation with another entity; 3) establish itself as a non-profit entity but contract certain functions with other organizations; 4) establish itself as an independent non-profit entity without formal arrangements with other organizations. The BDM will continue to explore all of these options and work out any potential agreement with another entity. NCHS continues to support the consortium and will probably continue similar support, but this would allow us to expand our funding opportunities. Initial funds will likely come from membership dues.

Member comments, support? Concerns? Volunteers?

Claudia has experience in 501 application and bylaws and will volunteer help to help establish these. She believes that this will allow this organization to move forward and get grants and is willing to join the BDM. Roxanne shares concern about both the legal aspects plus issues of financial stability of organization. The workgroup discussed the hiring of staff and continued streams of funding. The BDM needs to do a business plan, to look at revenue streams, to consider dues in the very beginning, to hire staff, and construct an agreement with NCHS regarding staff for support. The executive director will have a strong leadership role in pursuing funding sources, grants, and contracts. There is not much downside to incorporating, but the Consortium should negotiate an agreement so it could maintain its entity, without being swallowed up by the incubator. Claudia commented that this is very consistent with what she has seen and we are on right track. Judy believes that federal support and leadership has hooked the group into all the federal entities and hope this continues. Members expressed concern that dues may be a problem for states as they are in fiscal difficulties. It is possible to have different member categories and make this reasonable for various entities. Some organizations have already pledged founding money. There seems to be some money out there, but it cannot be funneled to the Consortium as a government entity. It was also suggested that some of the member organizations might get these dues put into their cooperative agreements with federal agencies. Members who have additional suggestions, concerns, etc. should contact Marjorie, Walter, or Elliot. The Steering Committee can have another call if that is necessary.

What do you want from PHDSC and what can you contribute

Tom reiterated the need to get biographies from SC members, not just to aid with WRC, but in day-to-day dealings. These bios will help people in their networking and jobs. Just knowing what people do may help to help achieve goals.

Bob believes we have created a footprint in national landscape. The Consortium represents a way to bring issues forward and it is very important that we continue.

Barb stated it is important to have this leadership and provide consultations and move issues forward.

Kathy commented that local health department don't want to and often don't have time to think about this work, but it is very important to their work.

Kate expressed concern about the need to get more state and local representation, but they are scrambling and struggling for funding. Tom agreed those resources are difficult to find but the WRC interactivity may be one of those ways that locals can build camaraderie and get the help they need by connecting with their peers. They also are very concerned about privacy. We hope to be able to standardize the biographies somewhat so people can search better for what they need.

The Steering Committee expressed consensus to move forward with incorporation efforts. They urged the BDM to cover the bases but not burn bridges.

Review Draft agenda for Mar 2003 meeting – Hetty

The agenda has been arranged around three main topics: 1) presentations from workgroups; 2) status of organization – priorities plans and future of organization; and 3) action items and business planning. 3 presentations are planned: 1) HIPAA; 2) focus on business plans; and 3) preview of WRC. We also have a group dinner planned. The Hilton Alexandria is near the airport and the Metro station. The NCHS is trying to find funding for food, breaks, and meals as these are not funded by government agencies. NCHS is looking for sponsorship. Janet will send a note to the membership of EHI to inquire about sponsorship. The prototype of the WRC will be accessible to SC membership who want to participate in the WRC group, but will not be up for the public by the time of the meeting. Comments will be accepted

and there is money left in the contract to make changes as suggested by the group at the meeting. There were no further suggestions for the meeting at this time.

Action Items:

- Janet will send information to the NCHS staff regarding the committees at EHI and opportunities for participation.
- Suzie will send information regarding the PLANID to the listserv
- SC members to consider or nominate leadership for newly developing workgroups in NHII and Privacy
- Suzie will post information regarding WRC calls to the listserv
- Tom will post a format for the biographies of SC members – members need to submit their bios to the NCHS staff in that format
- SC members who have ideas for funding for either the Consortium or the WRC should contact Marjorie
- The WRC still needs a chair or co-chair. Volunteers or nominations to NCHS or Tom
- All SC members send concerns or suggestions about incorporation to Walter or Elliot
- Consider the need for a future call of the SC, and send to Marjorie
- Janet will post a note to EHI membership regarding sponsorship of the SC meeting in the spring. Other members may solicit sponsorship as well.
- Suggestions about the spring meeting to Hetty.

Adjourn