# Table of Contents

Agenda: Day 1 ................................................................................................................................. i
Agenda, Day 2 ................................................................................................................................. ii
EXECUTIVE SUMMARY .................................................................................................................. iii
Day One Business Meeting ............................................................................................................ iii
Day Two ........................................................................................................................................... v

**DAY ONE: PUBLIC HEALTH DATA STANDARDS CONSORTIUM, 2006 BUSINESS MEETING OF MEMBERS (March 27, 2006)** ................................................................. 1
   Business Meeting .......................................................................................................................... 1
   Executive Committee Reports ....................................................................................................... 1
   Executive Director’s Report ........................................................................................................... 2
   Membership Revenues Discussion ................................................................................................. 3
   Reports from PHDSC Committee Chairs ..................................................................................... 4
   Health Care Services Data Reporting Guide: Mr. Robert Davis .................................................... 4
   External Cause of Injury Committee: Dr. Arturo Coto and Ms. Starla Ledbetter ............................ 4
   Payer Type Committee: Dr. Amy Bernstein .................................................................................. 5
   Privacy, Security, And Data Sharing Committee: Ms. Vicki Hohner and Dr. Richard Urbano ....... 5
   Communication and Outreach: Ms. Michelle Williamson ............................................................. 6
   Other Updates ................................................................................................................................ 7
   PHDSC Website Forum ................................................................................................................... 8

**DAY TWO: STANDARDS UPDATES (March 28, 2006)** ............................................................. 8
   Standards Harmonization Project: Roundtable Discussion - Moderator Ms. Marjorie Greenberg .... 9
   Healthcare Information Technology Standards Panel (HITSP) Overview: Dr. Walter Suarez ........ 9
   The HITSP structure is the HISTP Panel, Board, and Project Team ............................................ 12
   National Standards Links and Resources ....................................................................................... 15
   HITSP Inventory of Standards Inventories: Ms. Michelle Williamson and Mr. Robert Davis ....... 16
   HITSP Biosurveillance Technical Committee: Dr. Arturo Coto and Dr. Lawrence Hanrahan ........ 18
   HITSP Biosurveillance Use Case Technical Committee ............................................................... 18
   Privacy and Security Project: Roundtable Discussion – Moderator Dr. Walter Suarez, PHDSC President 19
   Overview of Health Information Security and Privacy Collaborative (HISPC) Project: Dr. Anna Orlova 19
   Bringing Public Health to the Table: Ms. Vicki Hohner and Dr. Richard Urbano .............................. 20
   Business Plan: Roundtable Discussion - Moderators Dr. Lawrence Hanrahan, Treasurer and Dr. Martin LaVenture, Vice-President, State and Local Agencies ................................................................. 21
# Agenda: Day 1
Monday, March 27, 2006

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
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<tbody>
<tr>
<td>1:00pm – 1:30pm</td>
<td><strong>REGISTRATION</strong></td>
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<td>1:30pm – 1:45pm</td>
<td><strong>WELCOME AND INTRODUCTIONS</strong></td>
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<td></td>
<td>Walter Suarez, President</td>
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<td>1:45pm – 2:15pm</td>
<td><strong>REPORT FROM THE BOARD OF DIRECTORS</strong></td>
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<td>Walter Suarez, President</td>
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<td>Lawrence Hanrahan, Treasurer</td>
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<td>2:15pm – 2:45pm</td>
<td><strong>REPORT ON THE CONSORTIUM’S ACTIVITIES</strong></td>
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<td>Anna Orlova, Executive Director</td>
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<td>2:45pm – 4:15pm</td>
<td><strong>REPORTS FROM PHDSC COMMITTEE CHAIRS</strong></td>
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<td>Moderator: Martin LaVenture, Vice-President</td>
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<td>DATA STANDARDS: Robert Davis &amp; Starla Ledbetter</td>
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<td>Health Care Services Data Reporting Guide: Robert Davis</td>
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<td></td>
<td>External Causes of Injury Codes: Arturo Coto &amp; Starla Ledbetter</td>
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<td>Payer-Type: Amy Bernstein &amp; Judy Parlato</td>
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<td>PRIVACY, SECURITY &amp; DATA SHARING: Vicki Hohner &amp; Richard Urbano</td>
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<td>NATIONAL HEALTH INFORMATION NETWORK: David Ross &amp; Anna Orlova</td>
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<td>COMMUNICATION &amp; OUTREACH: Michelle Williamson</td>
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<td>Web-based Resource Center: Vivian Auld &amp; Michelle Williamson</td>
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<td>4:15pm – 4:30pm</td>
<td><strong>BREAK</strong></td>
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<td>4:30pm – 4:45pm</td>
<td><strong>Introduction to Website Forum</strong></td>
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<td>Traci Padgett, The Lewin Group</td>
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<td>4:45pm – 5:15pm</td>
<td><strong>Website Forum 1</strong></td>
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<td>5:15pm – 5:45pm</td>
<td><strong>Website Forum 2</strong></td>
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<td>4:15pm – 5:45pm</td>
<td><strong>Member Organizations Exhibits</strong></td>
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<td>5:45pm</td>
<td><strong>MEETING ADJOURNMENT</strong></td>
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<td>6:30pm – 7:30pm</td>
<td><strong>Happy Hour - The Inn &amp; Conference Center, University of Maryland</strong></td>
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<td>7:30pm – 9:00pm</td>
<td><strong>PHDSC BOARD MEETING &amp; DINNER</strong> - All members are invited</td>
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## Agenda, Day 2
Tuesday, March 28, 2006

<table>
<thead>
<tr>
<th>Time</th>
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<tr>
<td>8:00am - 9:00am</td>
<td><strong>BREAKFAST</strong></td>
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<tr>
<td>9:00am - 9:10am</td>
<td><strong>DAY 1 REVIEW AND INTRODUCTION TO DAY 2 ROUNDTABLES</strong></td>
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<td></td>
<td>Marjorie Greenberg, Vice-President</td>
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<td>9:10am - 10:30am</td>
<td><strong>STANDARDS HARMONIZATION CONTRACT: ROUNDTABLE DISCUSSION</strong></td>
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<td>Moderator: Anna Orlova, Executive Director</td>
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<td>Healthcare Information Technology Standards Panel (HITSP)</td>
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<td>Overview – Walter Suarez</td>
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<td>HITSP Inventory of Standards Inventories – Michelle Williamson/Robert Davis</td>
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<td>HITSP Biosurveillance Committee – Arturo Coto</td>
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<td>10:30am - 10:45am</td>
<td><strong>BREAK</strong></td>
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<td>10:45am - 12:30pm</td>
<td><strong>PRIVACY AND SECURITY CONTRACT: ROUNDTABLE DISCUSSION</strong></td>
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<td>Moderator: Walter Suarez, President</td>
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<td>Anna Orlova</td>
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<td>Vicki Hohner</td>
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<td>Richard Urbano</td>
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<td>12:30pm - 1:30pm</td>
<td><strong>LUNCH</strong></td>
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<td>1:30pm - 3:30pm</td>
<td><strong>BUSINESS PLAN: ROUNDTABLE DISCUSSION</strong></td>
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<td>Moderators: Lawrence Hanrahan, Treasurer and Martin LaVenture, Vice-President</td>
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<td>3:30pm</td>
<td><strong>MEETING ADJOURNMENT</strong></td>
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The annual business meeting of the Public Health Data Standards Consortium (PHDSC) convened in Hyattsville, MD on March 27-28, 2006 with the purpose of reviewing the past accomplishments of the Consortium and planning for the future. Day one of the meeting focused on Consortium business and PHDSC committee updates. Day two of the meeting consisted of briefings on national standards developments and discussion to explore strategies for the Consortium’s future development.

Day One Business Meeting

Dr. Walter Suarez, PHDSC President, acknowledged two incubating organizations that have been instrumental to the Public Health Data Standards Consortium: (1) John Hopkins School of Public Health that provides the major organizational support and infrastructure necessary for operating the Consortium; and (2) The National Center for Health Statistics (NCHS) that provides significant resources in terms of staff support and direct and indirect funding for Consortium activities. Ms. Marjorie Greenberg, Vice President for Federal Agencies, also acknowledged Consortium members and members of the Executive Committee, as well as the commitment of Dr. Orlova as Executive Director of the Consortium, thanking them all.

Executive Committee Reports

The Consortium had a good year with revenues of $111,367 and expenses of $87,000, resulting in a net income of $24,367. The Consortium’s federal partners are contributing more than anticipated to the majority of the budget. Financial statements are based on cash-based accounting, not accrual, raising issues of cash flow. Revenues are generated from four main categories: 1) membership dues; 2) grants and contracts; 3) $24,999 from a Small Conference Grant from the Agency for Healthcare Research and Quality (AHRQ) for the 2005 Annual Meeting; and 4) the Health Resources and Services Administration (HRSA) contract to develop prototypes of the health record in the 21st century. The Consortium will expect the same amount of grant revenue from HRSA next fiscal year, plus a sub-contract from the National Coordinator’s Office for a data standardization contract by June 2006. Another future revenue category, “services”, needs to be explored.

Executive Director’s Report

Dr. Anna Orlova thanked AHRQ and HRSA for their support. NCHS supported the Lewin Group to develop the Web-based Resource Center and also supported the work of the National Association of Health Data Organizations (NAHDO). Additionally, the Consortium’s committees are essential, with volunteers contributing their time and expertise.

Two national initiatives (the privacy and standards harmonization contracts), will provide some revenues. Ideally, Consortium staffing should include 3 or 4 full-time employees (the Executive Director, a person for the harmonization contract, and a person for the privacy contract, administrative support, including a webmaster to be paid from the $100,000 that should be available for operations). As we grow in budget and staffing, we would need to evaluate the role of Johns Hopkins as incubator of the Consortium.
**Membership Revenues Discussion**

The difference between contributing and general membership dues was delineated: contributing members have a guaranteed seat on the Board of Directors and general members do not; the latter elect Board members from within their respective membership class (e.g., State and local government agencies). The Consortium is seeking more members to join as general members. Individual memberships also are available, although they do not include membership on the Board. Options for membership structures were discussed, including an umbrella arrangement in which multiple organizations pool resources to make the Consortium the center for standards. The Consortium continues to struggle to get state/local agency memberships. It was suggested that the Consortium explore medical centers as members, especially related to medical information technologies.

**Reports from PHDSC Committee Chairs**

The need for an organization for public health data standards at the national level was emphasized. The Consortium is growing financially, but knowledge wealth is value-added, as the Consortium provides leadership and expertise to standards activities. At the October 2005 PHDSC retreat, a new organizational structure was established to include an oversight committee (chaired by Mr. Robert Davis and Ms. Starla Ledbetter) to connect and coordinate the standards work across committees. Others were invited to assist. Highlights of the PHDSC Committee Chair reports are as follows:

- **Health Care Services Data Reporting Guide:** The PHDSC is recognized as a legitimate player in national standards, including X12N and Health Level 7 (HL7). These entities are comfortable with Mr. Davis’ representation of public health and state reporting interests, both personally and as a content expert. Mr. Davis was sure to construct the new 837 guides to support the reporting of ICD-10-CM and ICD-10-PCS. (He noted that Michelle Williamson was the mastermind behind this, identifying this important opportunity). The work was done through Consortium, and X12N could not have supported ICD-10 classifications without this.

- **External Cause of Injury Committee:** The purpose of the External Cause of Injury Committee (ECIC) is to promote the collection and reporting of standardized external cause of injury codes and to promote the use of external cause of injury codes by public health practitioners and researchers. The ECIC updated the white paper titled, “External Cause of Injury Codes---Compelling Stories”. The ECIC is working with the Web-based Resource Center (WRC) on development of the ECIC committee page. The Lewin Group contract will support a web-based tutorial, and the ECIC is exploring a possible collaboration with the Council of State and Territorial Epidemiologists (CSTE) Injury Control and Prevention committee.

- **Payer Type Committee:** The workgroup has developed a methodology to standardize the “source of payment” categories. Mr. Davis is moving it forward to include this as an external code set in the joint meeting of the National Uniform Claims Committee (NUCC) and the National Uniform Billing Committee (NUBC). The payer typology code set is more of a data analysis tool than a data collection tool like ICD, permitting users to map payer type codes into comparable categories. The NCHS/CDC is proposing to maintain the code set, as an organization with the resources to update it and keep a paper trail of the decision process. The national PlanID standards would not negate the need for this payer typology.

- **Privacy, Security, And Data Sharing Committee:** The mission of the Privacy, Security, and Data Sharing Committee is to represent public health and health services research interests in privacy and security issues and address balancing patient privacy, confidentiality, and security with the need for useful data for public health and research. Under a HRSA grant, the committee completed and posted on
the WRC three local health privacy case studies and also updated the Consortium website with up-to-date privacy materials. There are plans to develop a web portal for educational issues on privacy.

- **Communication and Outreach Committee:** This committee is a new PHDSC Committee with a Subcommittee, the Web-based Resource Center. The objectives of the committee are to market the Consortium and explore communications opportunities, including a revamping of the web resource center. The Consortium would like to secure a Webmaster when funding is stable for daily maintenance of the WRC.

**Other Updates**

**Business Process Requirements for Public Health**
Robert Wood Johnson Foundation is introducing a new program for state/local health departments. The Public Health Informatics Institute (PHII) would like to partner with the Consortium to define requirements specifications for key parts of public health practice. Dr. Dave Ross will drill down into several public health domains and processes, offering grants for state/local agencies to work with them to develop the requirements. Rigorous analysis and a consensus by those who practice public health have been needed for a long time.

**PHDSC Website Forum**
Meeting participants then engaged in a hands-on evaluation of the Web-based Resource Center site and provided feedback that will guide the WRC and the Lewin Group in further enhancement of the site. The next step will be a usability study of the site before it is goes to alpha and beta testing. The site is expected to be live by the end of August.

**Day Two Standards Updates**

On the second day, Ms. Marjorie Greenberg called the meeting to order. She summarized the board meeting from the prior evening, March 27, 2006:

- The Consortium is in the best financial shape since its inception, due to a combination of increased membership and several important contracts.
- The current board officers were re-elected for another year’s term.

The Consortium has been a leader in identifying important data needs for quality, for national health information infrastructure, for health promotion, and disease prevention. Ms. Greenberg thanked all of our chairs and co-chairs for doing a terrific job. The Consortium wants to partner with all groups around common areas of interest, not duplicating, but leveraging our efforts in the area of data standards. Dr. Walter Suarez, PHDSC President, proposed that the Consortium vote on a commendation to our member, Johns Hopkins Bloomberg School of Public Health, for the phenomenal support that they provided to the Consortium and in incubating the Consortium. The attendees approved this unanimously.
Standards Developments: Reports

Health Information Technology Standards Panel (HITSP) Overview

The Consortium is actively engaged in the standard harmonization projects to create the interoperability needed in a Nationwide Health Information Network (NHIN). The components of standards harmonization include compliance certification, nationwide health information network, privacy and security and IT adoption. The American Health Information Community (AHIC), an advisory body to the Secretary of Health and Human Services, chaired by Secretary Leavitt, will oversee priorities down through the system, to the Office of the National Coordinator and their funding sources to support the various contracts that they created to implement the NHIN, including the Standards Harmonization Contract, the Health Information Security and Privacy Collaboration (HISPC); the Healthcare Information Technology Standards Panel; the Certification Commission on Healthcare Information Technology (CCHIT).

The HITSP contract was awarded to the Standards Harmonization Collaborative comprised of about 18 organizations. HITSP’s mission is to serve as a cooperative partnership between the public and private sectors for the purpose of achieving a widely accepted and useful set of standards. The Panel will assist in the development of the U.S. NHIN and address issues such as privacy and security. Dr. Walter Suarez was elected to the Board of the Standards Panel of the Healthcare Information Technology Standards Panel (HITSP) as the public health representative.

Panel 1

HITSP Inventory of Standards Inventories

An overview of the Inventory of Standards Inventories Committee work under the HITSP process was reviewed. The charge of the committee was to gather together existing standards inventories from various national entities and suggest the best way to maintain the inventory to inform harmonization efforts. The committee has created a worksheet to delineate a simple standards taxonomy (content, structure, messaging and function), and domains (e.g., clinical, administrative, financial, research, public health). This work was presented to the HITSP technical committee in Chicago. Collaboration between the PHDSC and the National Alliance for the Health Information Technology (NAHIT) will make the inventory of standards more complete and include links, and a web tool.

HITSP Biosurveillance Technical Committee

The workgroup is developing a glossary of terms for surveillance use cases and then a biosurveillance framework. They worked with the Council of State and Territorial Epidemiologists (CSTE) and the National Notifiable Disease Surveillance System reportable conditions. The New York City reportable conditions were cross-walked and identified as the gold standard. Public health participation in the technical committees is essential.

Panel 2

Overview of Health Information Security and Privacy Collaborative (HISPC) Project

The Privacy and Security project involves primarily a contract that the national coordinator awarded to engage Research Triangle Institute (RTI) in North Carolina. They received over $12 million for an 18 month project. The governors of the states will be the facilitators in implementing 40 or so grants or sub-contracts that will be issued by RTI over the next month. Public health has a very critical role. This project will guide the process of
health information exchange. The greatest value of this whole project will be that each state will learn what the other 39 states are doing with respect to some of the same issues that they deal with.

**Bringing Public Health to the Table**

Through the Consortium’s letter to governors regarding the HISPC project, points on Public Health 101 and what Public Health is about were communicated. The letter is very strong and the response from several states was positive, with support from the Consortium welcomed. Consortium members were invited to participate on a committee created by AHIMA to formulate scenarios for discussion at the state level, as public health is under-represented on this committee. A use case scenario for privacy should be a simple one, then layering on communicable disease, mental health, chemical dependency, etc. as additional complexities, building from the single scenario.

**Business Plan: Roundtable**

The Consortium business plan discussion concluded the meeting. The Consortium should take advantage of the depth of experience, the expertise from inside the organization. Through the communication and outreach committee, the Consortium should prioritize outreach to state and local agencies to become members, focusing on the ones that already have an informatics focus. Issues of organizational structure and the PHDSC’s relationship with other organizations were discussed, with emphasis on avoiding duplicating efforts of other organizations.

A multi-state year plan could include linking with other national efforts and entities and expanding the Consortium’s capacity and scope of work. Strategies mentioned included obtaining a federal indirect cost rate, developing private sector and foundation partnerships, and lowering membership fees for state and local health departments. The PHDSC should clarify its products and define a visual roadmap, showing the various organizational relationships and focus areas.

The Public Health Data Standards Consortium is committed to bring a common voice to the public health community and to the national effort for standardization of healthcare information. The Consortium does have a niche in the standards process. It represents public health at the state and federal levels in X12, HL7, NUCC and NUBC.

Challenges to moving forward are many. The Consortium relies on volunteers for much of its work. Staff and funding constraints limit its ability to generate revenues through services, such as webcasts and audiocasts.

The discussion highlighted the need to position the Consortium within the industry as a strong voice for public health and public health data standards and to bring a single voice for public health throughout the standards process.

Staff and Board members thanked participants and adjourned the meeting.
Call to Order
Dr. Anna Orlova called the meeting to order at 1:32 pm. Ms. Marjorie Greenberg thanked staff and welcomed attendees to the NCHS auditorium. Reception and dinner board meeting arrangements were reviewed. Sign up sheets for committees were also circulated.

Ms. Greenberg discussed where the Consortium is today and where we are going in the next few years. She then introduced Dr. Walter Suarez, President of the Consortium. Dr. Suarez noted that much has happened since last year, when we joined forces with the E-health Initiative for our annual meeting. Today, we look back at where we are with our committee activities, and look forward to tomorrow, where we are going.

Business Meeting
Dr. Suarez acknowledged two incubating organizations that have been instrumental to the Public Health Data Standards Consortium: (1) John Hopkins School of Public Health that provides the major organizational support and infrastructure to keep the Consortium operating; and (2) The National Center for Health Statistics (NCHS) that provides significant resources in terms of staff support and direct and indirect funding for Consortium activities. Ms. Greenberg also acknowledged Consortium members and members of the Executive Committee, as well as the commitment of Dr. Orlova as Executive Director of the Consortium, thanking them all. Meeting participants then introduced themselves.

Executive Committee Reports
Dr. Larry Hanrahan, Director of Public Health Informatics & Chief Epidemiologist, Wisconsin Division of Public Health and Treasurer of the Consortium, presented the budget. The Consortium had a good year with revenues of $111,367 and expenses of $87,000, resulting in a net income of $24,367. The Consortium’s federal partners are contributing more than anticipated to the majority of the budget, combined with less expense than estimated. This report period spans through the past nine months, as last year’s meeting was held at the end of May 2005. Financial statements are based on cash-based accounting, not accrual, raising issues of cash flow. Johns Hopkins pays for the Executive Director’s salary every 6 months and the Consortium pays what they can afford for other operational expenses. The fiscal year is July 1 through June 30. Since net income is expected this year, a motion was made to approve the purchase of a desktop computer for the Executive Director (around $2,500). The motion was seconded and approved.

Revenues are generated from four main categories: 1) membership dues; 2) grants and contracts; 3) $24,999 from a Small Conference Grant from the Agency for Healthcare Research and Quality (AHRQ) for the 2005 Annual Meeting; and 4) the Health Resources and Services Administration (HRSA) contract to develop prototypes of health record in the 21st century. The Consortium will expect the same amount of grant revenue from HRSA next fiscal year, plus a sub-contract from the National Coordinator’s Office for a data standardization contract by June 2006. Another future revenue category, “services”, needs to be explored. What kind of services can the Consortium provide to add revenues and meet the needs of its members?
Dr. Orlova thanked AHRQ and HRSA for their support. NCHS supported the Lewin Group to develop the Web-based Resource Center and also supported the work of the National Association of Health Data Organizations (NAHDO). Of course, the Consortium’s committees are essential, with volunteers contributing their time and expertise.

Dr. Orlova’s goal is $500,000 in revenues. A couple of national initiatives (the privacy and standards harmonization contracts), will provide some revenues. Ideally, Consortium staffing should include 3 or 4 full-time employees (the Executive Director, a person for the harmonization contract, and a person for the privacy contract, administrative support, including a webmaster to be paid from the $100,000 that should be available for operations). As we grow in budget and staffing, we would need to evaluate the role of Johns Hopkins as incubator of the Consortium.

Dr. Orlova then presented an overview of Consortium projects and products; the Consortium’s organizational chart (approved by the Board in January 2006), and highlighted the Consortium’s productivity, historically as compared to the past 13 months (from January 2005).
Dr. Orlova remembered when she attended her first Consortium meeting in 2002 and thanked Mr. Robert Davis who inspired her to become active in the Consortium. We know about public health data standards, but what are public health data and what is public health? The Consortium is formulating definitions for the field and communicating these back to the larger standards communities.

Dr. Suarez thanked Dr. Orlova for the report. He acknowledged her participation in national forums and national projects funded by AHRQ and the Office of the National Coordinator.

**Membership Revenues Discussion**

In response to a question, Dr. Orlova described the difference between contributing and general membership dues. The main difference is that contributing members have a guaranteed seat on the Board of Directors and general members do not; the latter elect Board members from within their respective membership class (e.g., State and local government agencies). The Consortium is seeing more members to join as general members. Individual memberships are available, classified as “Other” general membership dues.
Several of the meeting attendees stated that membership revenues are very difficult to maintain and that other organizations also are involved in data standards. Could the Consortium be a true umbrella, with each organization paying a portion of their dues to the Consortium for standards-related activities? In a sense, this would be pooling resources to make the Consortium the center for standards. The Consortium continues to struggle to get state/local agency memberships. It was suggested that the Consortium explore medical centers as members, especially related to medical information technologies.

**Reports from PHDSC Committee Chairs**

Dr. Marty LaVenture moderated the PHDSC Committee Chair discussion. Dr. LaVenture was reminded of the quote, “May you live in interesting times”. From a standards perspective, we are certainly “living in interesting times”. We need an organization for public health data standards at the national level. The Consortium is growing financially, but knowledge wealth is value-added, as the Consortium provides leadership and expertise to standards activities. He welcomed advice to committees to collectively make our efforts stronger.

At the October 2005 retreat, the Consortium had discussed how committees can better work together and a new organizational structure was established. The new organizational structure will have an oversight committee (chaired by Mr. Robert Davis and Ms. Starla Ledbetter) to connect and coordinate the standards work across committees. A new value proposition of the Consortium is global—and Mr. Davis and Ms. Ledbetter are seeking help from others for ideas on how to provide the coordination and oversight.

**Health Care Services Data Reporting Guide: Mr. Robert Davis**

Mr. Davis pointed out that from the inception of the Consortium in 1999 to present, there has emerged much progress in the Consortium’s position in national standards. “We are players, with four implementation guides in X12N. Public health is no longer just an “add on”. Health Level 7 (HL7) and the American National Standards Institute Accredited Standards Committee X12N are comfortable with Mr. Davis, both personally and as a content expert. Both organizations look to him to mediate and be part of the solutions. This did not come cheap—or easy—or overnight.

In April, the Technical Assessment Subcommittee of X12 will meet. This is the only subcommittee that needs to provide approval for all the guides to become standards. All other public review, response, and workgroup approvals have been achieved! With this subcommittee’s approval, the Guide will become national standards. We are a part of the process, and as such, all parts of the guides are aligned more than ever before.

Mr. Davis was sure to make the new 837 guides support the reporting of ICD-10-CM and ICD-10-PCS. He noted that Michelle Williamson was the mastermind behind this, identifying this important opportunity. The work was done through Consortium, and X12N could not have supported ICD-10 classifications without this.

In summary, we are players in HL7 and X12N and these organizations are no longer looking at us as a threat. We will be sure to keep enhancing this position.

**External Cause of Injury Committee: Dr. Arturo Coto and Ms. Starla Ledbetter**

The purpose of the External Cause of Injury Committee (ECIC) is to promote the collection and reporting of standardized external cause of injury codes and to promote the use of external cause of injury codes by public health practitioners and researchers. E-codes are important for injury surveillance, prevention and control, cost containment, and public health research.
The ECIC updated the white paper titled, “External Cause of Injury Codes---Compelling Stories”. The ECIC is working with the Web-based Resource Center (WRC) on development of the ECIC committee page. The Lewin Group contract will support a web-based tutorial and the ECIC is exploring a possible collaboration with the Council of State and Territorial Epidemiologists (CSTE) Injury Control and Prevention committee.

**Payer Type Committee: Dr. Amy Bernstein**

Dr. Amy Bernstein presented an overview of the Payer Type Committee’s work. For some time, the Consortium has been seeking a more standardized “source of payment” categorization and developed the proposed typology while waiting for the HIPAA PlanID to come about. Since progress is very slow with the HIPAA PlanID, the Consortium moved ahead with developing their own.

The typology was presented for discussion. Mr. Davis is moving it forward as an external code set in the joint meeting of the National Uniform Claims Committee (NUCC) and the National Uniform Billing Committee (NUBC). The X12N workgroup did not initially understand the purpose of the typology, but does now. In June, the typology will be considered as an external code list to augment the current X12N payer code list which is not usable for public health and research. As with the present on admission indicator, the payer typology would be constructed within the healthcare services data reporting guide and migrated to the other guides. Given that source of payment differs across states and the fact that current HIPAA transactions do not reference this code set, what is our strategy for the future? Two strategies were identified: 1) The NCHS/CDC is proposing to maintain the code set, as an organization with the resources to update it and keep a paper trail of the decision process; and 2) the Consortium should write a letter to DHHS and NCVHS to recommend the typology as part of the core elements.

Use case applications were discussed. Dr. Bernstein considers the payer typology code set as more of a data analysis tool than a data collection tool like ICD, permitting users to map payer type codes into comparable categories. The Georgia Hospital Association has proposed to pilot the adoption of the list. As it is a hierarchical list, they will not use the detailed codes but will adopt this methodology for the first 2 digits. The typology could be used in national surveys, like the National Hospital Medical Care Surveys maintained by NCHS. It may be included in the next version of the Health Care Services Data Reporting Guide. DHHS is backing off publishing the NPRM for the Health Plan ID. It apparently is not in high demand in the industry, so there is no clearly defined need as for other standards, (like the National Provider Identifier (NPI)). However, PlanID standards would not negate the need for this payer typology.

Congress charged the Secretary to come out with a national payer ID. Therefore, it is in the law, even though the industry is not pushing to move it forward. The payer typology committee talked with staff working on the payer ID to align categories in both standards before the Payer ID is ultimately issued. Apparently, the Payer ID staff has cited confidentiality as the reason for not sharing information, but it appeared as if the staff was more concerned about designating the type of plan (managed care vs. PPO vs. IPA) than defining the plans. Payer type maps to the type of contract, which is very difficult to do. Incentives vary, depending on type of contract. Amy reported that the committee is going with the lowest common denominator and will not attempt to differentiate between contract differences. However, it would be possible to extend to many digits if the contract details are known, and then to roll the records up to general types of plans for analysis purposes.

**Privacy, Security, And Data Sharing Committee: Ms. Vicki Hohner and Dr. Richard Urbano**

The mission of the Privacy, Security, and Data Sharing Committee is as follows:
• Represent public health and health services research interests in privacy and security issues
• Address balancing patient privacy, confidentiality, and security with the need for useful data for public health and research.

The focus of the committee is on activities related to privacy, security, and data standardization, including the implementation of the HIPAA privacy and security rules. Under a HRSA grant, the committee completed and posted all three local health privacy case studies and updated the Consortium website with up-to-date privacy materials. There are plans to develop a web portal for educational issues on privacy.

Other committee activities include the following:

• Proposed involvement with the RTI privacy and security contract from the Office of National Coordinator;
• Wrote and distributed letters to all state governors to encourage public health and public sector participation, outlining major privacy concerns unique to public health, and offering the Consortium’s support in the effort;
• Participated on the AHIMA Security and Privacy Task Force under the Research Triangle Institute contract, generating draft health information workflow and data sharing scenarios;
• Wrote articles for the Association of State and Territorial Health Officials (ASTHO) newsletters;
• Co-writing a white paper on cross-state data exchanges with ASTHO;
• Developing a joint national communications effort to communicate with both the public health sector as well as to groups involved in national efforts.

The committee will continue to monitor and look for avenues of involvement and/or participation in the national privacy/security efforts.

Excerpt from the Privacy, Security, and Data Sharing Committee Letter to Governors regarding the Health Information Security and Privacy Collaboration (HISPC) project:

• The Consortium is also prepared to work with your state and your office in the coming months in any other manner that may assist you in this important effort.
• Specifically, the Consortium will be pleased to provide expertise and additional input from the public health perspective, and assist your state in evaluating the findings and recommendations for public health fit.
• The Consortium is also available to discuss other avenues of participation that states may find of value as they begin to implement this important project.

Communication and Outreach: Ms. Michelle Williamson
Ms. Michelle Williamson presented the Communication and Outreach Committee report. Ms. Sally Klein is the co-chair and could not attend today’s meeting. This committee is a new PHDSC Committee with a Subcommittee, the Web-based Resource Center. The Committee was established in response to recommendations made during the October 2005 Interim PHDSC meeting of the Executive Committee and
Committee Chairs. The objectives of the committee include the following:

- To Market the Consortium
- To explore options for increasing media coverage of the Consortium such as through member organizations and other mechanisms
- To explore development of a quarterly newsletter to disseminate to member organizations and others interested in public health data standards issues

Strategies include developing an email distribution list for the quarterly newsletter. The Communication & Outreach Committee hopes to receive feedback on the newsletter idea and whether it might eventually increase membership in the Consortium. We will invite current members to refer other organizations as members in order to increase member participation in the various Consortium committees.

Other activities will be directed to marketing and increasing visits to the Consortium’s Web-based Resource Center (WRC). We will plan to create and send a push-type message to the lists to announce the “new and improved” PHDSC website and updates or additions. We are working on the 3rd Generation of the Website, with the following enhancements and initiatives:

- Redesigned Home Page
- Enhanced Committee’s Pages and Hot Topics
- Modified Membership Page
- Privacy Policy
- Educational Materials for External Cause of Injury Codes Committee
- Privacy, Security & Data Sharing Committee Products
- Conducted Usability Study
- Collaborated with Chairs of the PHDSC Committees for Future Content Development

The Consortium would like to secure a Webmaster when funding is stable for daily maintenance of the WRC. The Webmaster would report to the PHDSC Executive Director and the part-time salary is estimated to cost $20,000 to $25,000 per year.

**Other Updates**

Robert Wood Johnson Foundation is introducing a new program for state/local health departments. The Public Health Informatics Institute (PHII) would like to partner with the Consortium to define requirements specifications for key parts of public health practice. The new national program serves as an example of why the Consortium is a useful organization. We need agreement about public health work, a uniform understanding of how it is done, and requirement specifications with linkage to community care.

Public health covers a broad front with data interests in many domains. None of the domains have ever been specified to say this is what we do in public health, why and how. Dr. Dave Ross will look into a couple of those areas, offering grants to have state/local agencies work with them to develop the requirements.
The Electronic Health Record white paper table shows the results of a survey of local health departments in which 23 programs were supported. Many of these are direct care and only 30 percent of the services are public health. So, we estimate about 70,000 programs relevant only to public health programs, not counting direct services. Immunization Registry, blood registry are examples and there are many more. We will need to find commonalities in these programs, not differences, then standardize processes in one health department and then others.

PHII work will lead to a comprehensive description of the business processes and information requirements to support the processes for several domains of public health practice. Then the Association of State and Territorial Health Officers (ASTHO) and National Association of City and County Health Officers (NACCHO) will bring a consensus endorsement of these domain business processes. The information can be used as format requirements document for vendors and as a users perspective for certain public health information systems. PHII will ask the federal agencies to be partners and collaborators in the new project. Rigorous analysis done by those who practice public health has been needed for a long time.

**PHDSC Website Forum**

Ms. Michelle Williamson, Co-chair of the Web-based Resource Center together with Ms. Traci Padgett, Lewin Group, presented the newly redesigned Public Health Data Standards Consortium Web-based Resource Center website. Meeting participants then engaged in a hands-on evaluation of the site and provided feedback that will guide the WRC and the Lewin Group in further enhancement of the site. The next step will be a usability study of the site before it is goes to alpha and beta testing. The site is expected to be live by the end of August.

**DAY TWO: PUBLIC HEALTH DATA STANDARDS CONSORTIUM, 2006
BUSINESS MEETING OF MEMBERS (March 28, 2006)**

**Day 1 Review and Introduction To Day 2 Roundtables: Ms. Marjorie Greenberg, Vice President, PHDSC and Federal Agencies Representative**

On the second day, Ms. Marjorie Greenberg called the meeting to order. She summarized the board meeting from the prior evening, March 27, 2006. The Consortium is in the best financial shape since its inception, due to a combination of increased membership and several important contracts. The current board officers were re-elected for another year’s term. Ms. Greenberg encouraged other members to run for office next year. She especially thanked Dr. Walter Suarez, the Consortium President. He has devoted many hours to the Consortium, putting his heart and soul into it and eventually making the ultimate sacrifice when he moved from Minneapolis to sunny Washington D.C. so he could be closer to Johns Hopkins and the NCHS.

Ms. Greenberg recapped the previous day’s meeting. We heard from Mr. Robert Davis and others that the Consortium is now a player in national standards initiatives. Our goal was to have a voice at the table, and we’re not only at the table but sometimes we’re at the head of the table. The Consortium has been a leader in identifying important data needs for quality, for national health information infrastructure, for health promotion, and disease prevention. Committees reported on their accomplishments, not only in the past year but since their inception:

- The Health Care Services Data Reporting Guide, one of the Consortium’s first projects, is now fully recognized as one of the approved (external) guides.
• In the last year, we have really made progress on the payer typology, which is moving towards an external code list and is much improved over the current X12N list, which does not meet the needs of public health.

• Injury data is among the most important in public health and sometimes it’s the least appreciated or well recorded, so the ECIC work is an important contribution.

• We also saw that our Web-based Resource Center is making great strides. And again, we’re very grateful to Michelle Williamson and also to Vivian Auld. And we heard that Ms. Auld is stepping down so we will be looking for a new co-chair for the Web-based Resource Center.

• We’ve added security to our portfolio in the Privacy and Data Sharing Committee. We’ve made inroads in the national initiative to promote cross-state data sharing through our privacy, security, and data sharing committee with active involvement in the RTI project and the Office of the National Coordinator.

So we want to thank all of our chairs and co-chairs for doing a terrific job.

We also heard about some new opportunities possibly with the Robert Wood Johnson Foundation to work on defining business processes, and in particular commonalities. And we heard Dr. Dave Ross, our first Treasurer, say that the Consortium is necessary and a central organization. And of course, I certainly believe that.

We’re doing a lot with volunteers. If we’re going to move forward, we must build an organizational infrastructure. The first step is offering our Executive Director a full year’s contract for 100% of her time. We also need to get her some help. Hopkins has been an incredible incubator, but we would like to be able to be more independent. We have proposed a goal of a $500,000 budget.

We want to partner with all groups around common areas of interest, not duplicating, but leveraging our efforts in the area of data standards.

Finally, Dr. Walter Suarez proposed that the Consortium vote on a commendation to our member, Johns Hopkins Bloomberg School of Public Health, for the phenomenal support that they provided to the Consortium and in incubating the Consortium. This support is making it possible for the Consortium to become a standalone organization. The attendees approved this unanimously.

**Standards Harmonization Project: Roundtable Discussion - Moderator Ms. Marjorie Greenberg**

**Healthcare Information Technology Standards Panel (HITSP) Overview: Dr. Walter Suarez**

The Consortium is actively engaged in the standard harmonization project. Dr. Walter Suarez was elected to the Board of the Standards Panel of the Health Information Technology Standards Panel (HITSP) as the public health representative. HITSP is one of those activities that came out of the national effort to coordinate the implementation of interoperability throughout the healthcare system and create a Nationwide Health Information Network. All these activities are now starting to take shape.

The components of standards harmonization include:

• Compliance Certification
• Nationwide Health Information Network
• Privacy and Security
• IT adoption.

Slide 3 illustrates the sort of infrastructure components put in place to achieve standards deployment.

Slide 3: ONCHIT Health Information Technology Deployment Coordination

In the center is the whole concept of the coordination of policies, resources, priorities and trying to bring all of the different perspectives for the industry to the table, not just providers and payers, but also vendors and researchers and public health. The central focus of all this is ultimately for improving care to consumers, improving the quality and the cost of healthcare by promoting the efficiency of healthcare systems.

Slide 4 provides a high-level perspective of the various structural component organizations that have been created to facilitate the process. At the top is what is now known as the American Health Information Community (AHIC), an 18-member advisory body to the Secretary of Health and Human Services which is chaired by Secretary Leavitt. Through the AHIC, there is the flow of priorities down through the system, to the Office of the National Coordinator and their funding sources to support the various contracts that they created to implement this: the Standards Harmonization Contract, the Health Information Security and Privacy Collaboration (HISPC); the Healthcare Information Technology Standards Panel; the Certification Commission on Healthcare Information Technology (CCHIT), which has been underway now for about a year and a half; the
Nationwide Health Information Network (NHIN) contracts with four vendor organizations for the development and implementation of prototypes.

Slide 4:

HHS Health IT Strategy

So one of the messages we want to put out today is that we need to expand the Consortium’s role and participation in all these activities. We already have representation on both the Healthcare Information Technology Standard Panel and the Privacy and Security Collaborative. We will want to make sure that we also link to these other two efforts and look at the ways in which we will be able to do it.

The Healthcare Information Technology Standards Panel (HITSP) contract was awarded to the Standards Harmonization Collaborative, basically a collaborative of about 18 organizations led by ANSI in cooperation with strategic partners including HIMSS, Advanced - ATI, Advanced Technology Institute and a consulting firm, Booz Allen Hamilton.

This collaborative established what is known now as HITSP, the Healthcare Information Technology Standards Panel. The HITSP mission is to “… serve as a cooperative partnership between the public and private sectors for the purpose of achieving a widely accepted and useful set of standards specifically to enable and support widespread interoperability among healthcare software applications, as they will interact in a local, regional and national health information network for the United States.” The Panel will “… assist in the development of the U.S. Nationwide Health Information Network (NHIN) by addressing issues such as privacy and security within a shared healthcare information system.” HITSP will charter documents to service the cooperative partnership between sectors to achieve a useful and widely-accepted set of standards to enable interoperability among health care providers.
The HITSP structure is the HISTP Panel, Board, and Project Team.

**HITSP Panel:**
The Panel itself is really a (multi-sectoral) coordinating body with the ultimate responsibility to deliver all (permanent) contracts which include a series of use case reports illustrating how standards can be harmonized in very specific situations. The Panel will develop the harmonized implementation profiles and information policy, including all the supporting documentations, in the standards central report. Panel membership is free and available to anybody who wants to participate.

**HITSP Board:**
The Board represents all the standards and non-standards development organizations that were identified by the contract and the initial Panel. There are 21 members elected to the Board: seven from all standards development organizations; one clinician representative; one provider; one payer; one IT organization, one vendor, one researcher; one safety net provider; one purchaser; two consumers, and four government; and of course, one from public health. The Board is responsible for organizing the work of the Panel by establishing coordinating and technical committees, monitoring the progress of those committees in between meetings of the Panel, and recommending actions to the Panel.

**HITSP Project Team:**
These are projects providing support behind the structure, formed by the 18 organizations that originally formed this Standard Harmonization Collaborative, including the Consortium. The project team facilitates the meeting documents and then develops and begins to prototype and rally all the harmonization process. Most of the support is being provided right now by ANSI, in the form of the project coordinator and the project director, and HIMSS.

The committees are listed in Slide 5 below. The technical Committee is involved in developing and prototyping standards harmonization processes within those new spaces and within those topics that were given to us by AHIC, identifying breakthroughs. And we created separately what we called Coordination Committees, responsible for the development of the administrative process that allows for the standard harmonization to happen.
Slide 5: HISTP Structure – Committees

A more detailed list of committees are listed in slides 6 and 7 below:

Slide 6: HISTP Structure – Committees

<table>
<thead>
<tr>
<th>Committee</th>
<th>Terms of Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Business Planning</td>
<td>Design and develop a self-sustaining harmonization process to ensure future viability and appropriate evolution of the standards defined by this project. To be successful, the business plan must take into account the inevitable evolution of technology, healthcare provision models, and development of new or redefined government and industry models of operation and collaboration. The ongoing process must include appropriate representation from stakeholder organizations, and must be based on a balanced approach that applies sufficient stewardship and leadership without creating unnecessary overhead or bureaucracy.</td>
</tr>
<tr>
<td>Steve Lieber, HIMSS</td>
<td></td>
</tr>
<tr>
<td>Harmonization Readiness Characteristics</td>
<td>A Standards Coordination Committee is being chartered to develop a Harmonization Readiness Tool that will support these HITSP decisions. The tool will be used by the Technical Committees as they go through the refinement process. The Harmonization Readiness tool is a set of characteristics that will establish the readiness of a specific standard to stand as the harmonized standard for a given situation. The tool should be as objective as possible. At a minimum, the characteristics should address Developer Due Process, Domain Relevance (i.e., health care area), Market Adoption, Life Cycle Maturity. Obviously many of these characteristics are only relevant within the context of a specific situation. Harmonization Readiness is the act of applying the characteristics to specific standards in a way that will allow the HITSP to select the standard most ready for use as the harmonized standard for a specific sector of interoperability.</td>
</tr>
<tr>
<td>Lynne Gilbertson</td>
<td></td>
</tr>
<tr>
<td>Inventory of Standards Inventories</td>
<td>Gather together existing standards inventories from HIMSS, CHI, NIST, NAHIT, CSI etc and suggest the best way to maintain an ongoing educational standards inventory resource to inform our harmonization efforts. Example of a standard would be a web page with pointers to all other work, a consolidation of the work to date into the NIST Standards Landscape tool or other approach. In the future the work of the Standards Readiness committee on the maturity of standards could then use this resource as the basis for their work.</td>
</tr>
<tr>
<td>Audrey Dickerson</td>
<td></td>
</tr>
</tbody>
</table>
Slide 7: HISTP Structure – Committees

### HISTP Structure – Committees

<table>
<thead>
<tr>
<th>Committee</th>
<th>Terms of Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>International Landscape of HIT Standards</td>
<td>Catalog the healthcare information technology work done to date and lessons learned from international standards harmonization efforts.</td>
</tr>
<tr>
<td>Bill Braithwaite</td>
<td></td>
</tr>
<tr>
<td>Harmonization Process Management Committee</td>
<td>Provide focal point for gaining consensus on elements of the harmonization process, the dissemination vehicle and process, and the release schedule for harmonized-standards versions. Not Yet Panel Approved</td>
</tr>
<tr>
<td>Bio-surveillance, Consumer Empowerment, and EHR Technical Committees</td>
<td>Identify, and analyze gaps and duplications within the standards industry as they related to each specific Use Case; provide a description of the gaps, including missing or incomplete standards; provide a description of all duplications, overlaps, or competition among standards for the relevant use cases; provide a listing of all standards that satisfy the requirements imposed by the relevant use cases as well as testing criteria that shall be used to test the standard; submit these recommendations to HITSP for review, approval and resolution. Future phases of activity will focus on selecting, testing, and evaluating recommended standards to meet the relevant use cases, as well as prototyping, testing and evaluating ‘implementation guides’ for standards, including applicability criteria and adherence tests.</td>
</tr>
</tbody>
</table>

Slide 8 actually shows a little bit of the step-by-step HISTP process and products. At the beginning you see the meeting of the request for business driven implementation processes - the request to incorporate the standard into the harmonization process. The committee then defines the standards, and there’s development of a gap analysis for the relevant standards. At this back end of the process, the approved request and then the implementation instructions are disseminated and maintained.

It is important to note that the panel itself is not a standards development organization. The panel doesn’t develop standards. The panel doesn’t write the implementation guide, the way HL7 or X12 develop standards and write implementation guides. But there will be a Reference Implementation Guide that will document how the multiple standards or multiple sources will work together. It’s an integration guide.
In summary, the key messages for today are as follows:

- The Consortium is engaged and is involved at the HITSP Board level and plays a facilitating role in the Technical Committee.
- There is a strong need for state and local public health representation on the technical committees. We need subject-matter-expertise and to identify assistance to assure their participation.
- The Consortium needs to participate in ALL technical committees and in as many coordinating committees as possible.

Links and Resources:

HISTP Website: http://www.ansi.org/standards_activities/standards_boards_panels/hisb/hitsp.aspx?menuid=3#Document
ONCHIT Website: http://www.hhs.gov/healthit/
AHIC Website: http://www.hhs.gov/healthit/ahic.html
HISPC Website: http://www.rti.org/hispc
NHIN Website: (not yet established…)
CHI Website: http://www.hhs.gov/healthit/chi.html
CCHIT Website: http://www.cchit.org/

The Consolidated Health Informatics (CHI) Web site highlights the government initiative critical to the HITSP process, providing input into the standard harmonization process. And the Certification Commission on
Healthcare Information and Technology is very important. They already have published and are right now finishing the public comment period for certifying the ambulatory electronic health record. As a Consortium, we also want to be in very close league to the certification commission, as they will give a stamp of approval for a product to be considered interoperable, certified to interoperate with others. That stamp of approval is going to cost the organization $50,000 to $70,000, a significant amount of money, to be certified. And certainly there would be the opportunity to identify products that are specifically geared to public health that work through networks like a Consortium’s certification. This credentialing process could be identified as a mechanism to provide them also with a stamp of approval from the Consortium of a product that interoperates for public health purposes. So it’s an opportunity that I think from a business plan perspective could create some possibilities.

**HITSP Inventory of Standards Inventories: Ms. Michelle Williamson and Mr. Robert Davis**

Ms. Michelle Williamson and Mr. Robert Davis provided an overview of the Inventory of Standards Inventories Committee work under the HITSP process. The charge of the committee was to gather together existing standards inventories from HIMSS, CHI, NIST, NAHIT, CSI, etc. and suggest the best way to maintain the inventory to inform harmonization efforts.

They created a worksheet with basic descriptors and categories to list inventories

- Basic (description, type, numbers, source, availability)
- Simple taxonomy (Content, structure, messaging and function)
- Domains (e.g., clinical, administrative, financial, research, public health . . .)

They presented a worksheet with some basic categories in most public health metrics (such as descriptions, (height), number, (forces)) in sample domain areas. This work was presented to the HITSP technical committee in Chicago. Ms. Williamson presented a few examples of what the Inventory Committee thinks would fit in the various domains:

- The contact information model standard is a standard much like the reference information model and some of these (MPM) and (SPM) standards.
- The information interchange includes standards such as the HL7 and X12N messaging standards, (MPGET).
- Terminology content definition, standards or set codes includes (IPV), (CPT), (SNOMED), (RX NORM) for a few examples.
- EHR functional standards.

To identify standards for the inventory, we included things such as the Federal Employee Identification Number and the National Provider ID. Functionality and business process include those things that Dr. Suarez mentioned earlier. For the committee, part of the process was collecting some standard inventory. Now we’re reviewing feedback from others - from those participating in the committee, on inventory - standard inventory.
The National Alliance for Health Information Technology (NAHIT) also talked about their standards directory. And you can see from the slide (Slide 9), their directory contains two primary types of entry, and also standard publication.

Slide 9

A collaboration with NAHIT is being considered, to use this as a resource, as a tool merging the Alliance Standards Directory content into the NIST Landscape tool. The Alliance would contribute its entire collection on healthcare standards, SDOs, web links and other information and the NIST would contribute the Landscape web tool. The result would be a comprehensive resource of health care standards information to serve as a starting point for SDOs and others to extend and manage relevant health care standards information.

That’s where we stand. We’re at a point where we’re looking for additional guidance; we’ve gathered some information, but we want to assure that this really is the outcome that the HITSP is looking for to help in the process.

Mr. Davis spoke on next steps. He pointed out a famous quote from Ms. Greenberg: “The good thing about standards is there are so many to choose from.” I think our inventories prove that that we have that. We need to make sure that Public Health standards are included in these inventories. If we decide that we want to be different, that we’re different because “we’re Public Health”, then we risk being excluded from the process. It is a really important time that we make sure people know that we’re special but not different and that we get included into these initiatives and that we don’t separate ourselves because of our history, we don’t separate ourselves because of where we were.
Next, we need to step to the table to be part of the solution. We need to step forward. The Consortium is a
voice for what standards need to be in there for Public Health. We need to make sure that all relevant parties
are a part of the process.

**HITSP Biosurveillance Technical Committee: Dr. Arturo Coto and Dr. Lawrence Hanrahan**

Dr. Arturo Coto presented the biosurveillance use case standard inventory. He stressed the importance for
public health to be communicating with clarity, fully understanding the terms that we are using. He mentioned
that public health participation in the technical committees is essential---that Dr. Orlova is representing the
Consortium, but she is staff, not a representative of the Consortium, and as such, she cannot give her opinion as
a public health representative. Therefore, we need people to provide input and opinion. Arturo believes that the
science of public health and the practice of public health are the same; therefore, people who have practiced in
public health should be the messengers and the representatives.

Dr. Coto reported for the workgroup on reportable conditions. The schedule of deliverables is as follows in
Slide 10 below:

**HITSP Biosurveillance Use Case Technical Committee**

**Task and Deliverable Schedule**

<table>
<thead>
<tr>
<th>Due date</th>
<th>Task No.</th>
<th>Task Name Deliverable</th>
</tr>
</thead>
<tbody>
<tr>
<td>03/30/2006</td>
<td>1</td>
<td>Biosurveillance use case standards inventory Standards inventory</td>
</tr>
<tr>
<td>09/30/2006</td>
<td>2 2.3</td>
<td>Assess notifiable conditions reporting 1st draft 1st. draft 1st,</td>
</tr>
<tr>
<td>09/30/2006</td>
<td>2.3.1</td>
<td>requirements across a subset of states CIS / draft</td>
</tr>
<tr>
<td>03/30/2006</td>
<td></td>
<td>BIS data capture analysis Reportable conditions</td>
</tr>
<tr>
<td>03/30/2006</td>
<td>3</td>
<td>Glossary of terms: Biosurveillance use case Develop biosurveillance technical</td>
</tr>
<tr>
<td>09/30/2006</td>
<td>4</td>
<td>framework 1st draft?</td>
</tr>
</tbody>
</table>

The workgroup is developing a glossary of terms for surveillance use cases and then a biosurveillance
framework. They held calls with the Council for State and Territorial Epidemiologists (CSTE), inviting them
first to speak to the workgroup with CDC officials about what they have been doing with regard to reportable
conditions. The National Notifiable Disease Surveillance System reportable conditions and the New York City
reportable conditions were cross-walked and identified as the gold standard.

The discussion highlighted that the Consortium is grateful for those working in this area and that this is
nationally important. Not just the Consortium is struggling---but it seems that the nation is struggling in trying
to bring the resources to bear to address these absolutely critical issues.

CSTE reported that it is working very hard in the reportable disease domain and how unbelievably difficult it is.
In New York, public health has tried for the last 20 years to make up a list of what is reportable by labs and by
providers. The effort has failed at least on two occasions. It’s just a reflection of how difficult it is to come up
with what is reportable, who reports it, and what the standards are for reporting it. CSTE offered assistance to the workgroup.

**Privacy and Security Project: Roundtable Discussion – Moderator Dr. Walter Suarez, PHDSC President**

Dr. Walter Suarez introduced the second panel. Like the HITSP and standards harmonization efforts, privacy and security are not that different. The issues have created a lot of interest and challenges.

The Privacy and Security project involves primarily a contract that the national coordinator awarded to engage an organization called (RTI), the Research Triangle Institute out of North Carolina. They received over $12 million for an 18 month engagement.

**Overview of Health Information Security and Privacy Collaborative (HISPC) Project: Dr. Anna Orlova**

Dr. Anna Orlova gave an overview. The Consortium is very heavily engaged in these issues with our Privacy Security and Data Sharing committee. The governors of the states will be the facilitators in implementing 40 or so grants or sub-contracts that will be issued by RTI over the next month. Public health has a very critical role. Early on, the Consortium considered how the committee and the Consortium might be involved in the RTI contract for the privacy and security RFP. The Consortium wrote and distributed letters to all state governors to:

- encourage strong public health and other public sector participation
- outline some of the major privacy concerns for public health, especially those that differ from the private sector, and
- offer the Consortium’s support

The service networks and policy infrastructure necessary to enable secure data exchange across programs and states are just not there; this impedes consumer and agency understanding and trust, which are essential to data exchange. The purpose of the privacy contract is to identify variations in organization level privacy and security laws and practices that affect health information exchanges and identify best practices that enable exchange. These best practices will be incorporated into a proposed solution and practices with a negative affect on data exchanges will be identified with solutions. The goal is also to protect as much information as possible in health information exchanges to promote consumer and stakeholder support for these exchanges. The contractor, along with 40 states, will identify within the states, those business practices that affect health information exchanges, (proposed) solutions, and an organization plan for collaboration on the regional and national levels. At the end of this process, RTI will issue the final report. The result is that this project will guide this whole process in health information exchange. RTI and NGA, the National Governors Association, will establish a framework for data sharing. The purpose will be to maximize all the exchanges and identify solutions and collaborations.

The discussion underscored the fact that the result of this project will be that all stakeholders including state entities will have a full understanding of variations in privacy practices in their own communities in relation to other states. (States), through the use of stakeholder groups, will design practical solutions and implementation plans for preserving information security protection while implementing cross-state information exchange---necessary to optimize a nationwide health information prototype. States will have access to state, regional and national solutions. RTI received 43 applications as of today. In February 2007, RTI will hold the national
meetings to present solutions and plans for implementing the solutions, outline the variation, and outline
nationwide summary of how this will be done.

The discussion summary pointed out how the Consortium informed the governors and public health agencies
about the RFP and their role in the process. States often do not understand their own barriers, let alone the
global perspective of the health care industry and nation as a whole. This project will pinpoint the state issues,
concerns, laws, and make sure that they can identify needed corrections. The greatest value of this whole project
will be that one state will learn what the other 39 states are doing with respect to some of the same issues that
they deal with.

**Bringing Public Health to the Table: Ms. Vicki Hohner and Dr. Richard Urbano**

The major concern of the Privacy, Security and Data Sharing committee about the privacy RFP was that public
health may not be aware of what was happening since this was going to be an initiative driven out of the
Governors offices. So the committee crafted a letter that was sent out to all the governors to let them know that
public health needed to be involved in this, if it wasn't already. Dr. Richard Urbano did a little research in
Tennessee and called up the voluntary Regional Health Information Organization (RHIO) to ask if they were
talking to public health and the governor’s office. He was pleased to know that the health department was
working on the (RFP).

Though the letter was primarily about the RFP and the Consortium, it also embeds talking points on Public
Health 101 and what Public Health is about. It then highlights some concerns about the significant impact that
privacy and security have on public health. Privacy and security can substantially affect initiatives such as
creating child health profiles, surveillance activity, and particularly in the interpretation of the laws. Richard
noted that the letter is very strong and the response from several states was positive. They will welcome any
support and help that the Consortium can provide them throughout this process, because clearly we all are
experiencing new terrain in this project.

Ms. Hohner spoke about an effort that's just getting underway. The creation of private and security scenarios
are going to factor into this project. The scenarios will involve data exchange between different kinds of
partners and for different purposes, and the timeline for submitting them is very quick. The privacy and
security scenarios will be submitted to a second group that is responsible for generating conversations about
where privacy and trade barriers might exist in the data exchange process within and across the states.

Ms. Hohner signed up to be a part of the privacy and security scenario group, which only has four calls as it’s
happening very fast. She is concerned as there is almost no public sector/government representation. And they
need more than public health—the entire public sector needs to weigh in because there are a lot of things that
apply in the public sector in terms of rules and regulations; and all these may come up as barriers or
consideration that need to be factored into privacy issues.

Ms. Hohner stated that there is still room for people on the committee, as no public health folks were on a
recent call that she attended and they have only forwarded one scenario for public health, which is a small
picture of the entire public sector. She also requested help with one or two public health scenarios. The
committee wants to limit these, making them simple, yet so much data exchange in government is very complex
with many agencies and players. Immunization was one scenario forwarded in the discussion, and includes
special education, chronically-ill children needing medication at school, providers, and the public. Outbreaks
were also mentioned, as was the scenario of protective custody and foster care, with one of the most difficult populations in terms of record sharing.

A scenario based on the Consortium’s work with New York City was also suggested as a possibility. Should there be a scenario about HIV/AIDS because most states have more protected standards there? How about minors not necessarily related to the school? There are differences from state to state about what is a minor. Reproductive health laws vary from state to state. Even in exchanging data for treatment, state laws vary widely.

Ms. Hohner summarized. They are seeking examples of data exchange situations, clinical and otherwise, so that every state could evaluate how that would work if they stayed within the state’s restrictions, privacy laws, business practices, security. We are trying to start the conversation with these scenarios. Input is needed on how to make sure we have the representation in those scenarios and that people can assist by submitting a couple of paragraphs for scenarios.

It was suggested to identify several individual scenarios that are at a simple single transaction, like AIDS, and then start adding certain elements that increase the complexity of the scenario to expose the additional interaction between having AIDS and having limited health coverage or having Medicaid. If we create a single scenario that has 15 variables, we lose the impact of the added factor of each of the additional variables. So it might be helpful to just start with a simple scenario like patients with mental health, or patients with AIDS. Then layer on communicable disease, mental health, chemical dependency, etc. as additional complexities, building from the single scenario.

Business Plan: Roundtable Discussion - Moderators Dr. Lawrence Hanrahan, Treasurer and Dr. Martin LaVenture, Vice-President, State and Local Agencies

Dr. Marty LaVenture and Dr. Larry Hanrahan led the discussion, seeking guidance for a Consortium business plan, taking advantage of the depth of experience, the expertise that’s here, and noting how crucial that is to the organization. Are we an umbrella organization? What is the context when we consider the business planning?

- Our relationship with other organizations? We want to avoid doing the same thing that another organization is doing, wherever possible.
- Linking to other efforts, collaborating with those key organizations involved in public health informatics.
- The issues of balancing our mission with meeting deliverables are difficult to reconcile.
- The context of other organizations who are members. How do we come up with that product focus that leverages efforts of CSTE, or ASTHO, or CDC, but adds depth of expertise across the public health system?
- How do we achieve, maintain and assure that we will have the capacity to expand our scope of work?
- From a business planning point of view, how do we begin to look at it from a multi-year point of view, where do we want to be in Year 2 and Year 3 as we work incrementally to get there? Let’s begin to get a multiyear view of the process.

Regarding the RTI contract, besides scenario development, is there another role for the Consortium?
• Follow-up with states after the Privacy and Security/RTI awards are announced—both with states receiving and not receiving the project grants. Issues about authorization and patient control have implications for public health. It’s a way to follow-up with states and to engage privacy officers and security officers.

• Soon a Morbidity and Mortality Weekly Report (MMWR) report will be released, summarizing the HIPAA Privacy Rule status of every state public health agency in the country in terms of whether they declare themselves as a hybrid, a covered entity or a non-covered entity.

The Consortium has roughly $100,000 a year in revenues now. How do we make the funding opportunities happen so that we are at $500,000 or even greater in the coming years, in these very tight fiscal times? Can we expand the investment by our federal partners? There’s been a fantastic amount of investment in us but there are others out there we could easily make the case that we’re serving their needs as well. Strategies mentioned included:

• Obtaining a federal indirect cost rate.
• Assess private sector partnerships and develop a product attractive for that sector.
• Finally, getting state and local public health membership is important. Maybe we should actually lower the fee for state and local health departments just so that we can get them in.
• We need to target foundations for funding.

The market audience for state and local agencies will seem to be ones that already recognize an informatics function that might be good to participate in the collaborative standard efforts.

Discussion:

• Make sure our focus on the state and county level for membership is on those already actively engaged in health informatics initiatives.
• Begin targeting agencies with active standards and informatics activities first.
• Travel dollars to participate in Consortium meetings is more of a challenge than membership funds. Subsidizing member travel might be a good strategy. Even then, travel is tightly controlled in many states. We must emphasize to prospective members that they don’t have to travel to participate in the Consortium.
• We need to do a better job of communicating what the Consortium is doing for members and public health; also we need volunteers and participants more than we need the membership dues. We need a broader base.
• We still don’t actually know what our product is; we still don’t have that clear definition of what separates us from our member organizations. We also need a visual roadmap, showing the various organizational relationships and focus areas.

In summary, under the communication and outreach committee, we could prioritize outreach to state and local agencies to become members, focusing on the ones that already have an informatics focus. The Public Heath Informatics Institute (PHII) previously organized the public health information officers from each state. They had funding from RWJF to pool together an organization of these individuals. PHII would at least know who
the organizations are to target and then try to determine through conference calls or other outreach, what is the barrier to their joining and what kind of services would benefit them.

Getting the message out, about public health practice and the Consortium is the key. The Public Health Data Standards Consortium is committed to bring a common voice to the public health community and to the national effort to standardization of healthcare information. The Consortium does have a niche in the standards process. We represent public health at the state and federal levels in X12, HL7, NUCC and NUBC.

The Consortium’s very first product was an educational strategy. Our mission is to educate the public health community about the importance of standards and the standards community about the needs of public health. No other broad-based organization is doing this. Our challenges:

- We rely on volunteers for much of our work. If we have more people who can devote themselves fulltime or even halftime to this, we could go further.
- Funding does not support infrastructure. A few of us have organizations that were willing to fund it, but not all. So, we will continue to forge partnerships.

If we can try to engage all of our members on one of the areas that we support each other on, that will help us in two ways:

- It will solidify our relationship with the members
- Provide ideas about how we can offer that same kind of partnership to other organizations

Seeking input from all attendees, the following points were addressed:

- The educational component of the Consortium could provide for education with Webinars or audio casts reviewing specific emerging standards. The new National Provider Identifier, for example, is a possible topic.
- We could generate revenues from such an audio cast or a Webcast with a focused topic.

Dr. LaVenture and Dr. Hanrahan concluded the discussion and thanked the participants for their comments. In summary, they felt the discussion yielded excellent themes, which will be synthesized and circulated for comments from discussants and others. Both stated that they were pleased to be a part of the Consortium, to be officers, and to be leading the charge of defining the business plan.

The discussion helped describe the Consortium’s history and future direction and they hoped that this discussion can help document the concrete achievements, products, and roles of the Consortium and the goals and objectives for the business plan. We want to position the Consortium within the industry as a strong voice for public health and public health data standards and bring a single voice for public health throughout the standards process.

The meeting was adjourned.