



Public Health Data Standards Consortium
Consortium Operating Structure
Discussion Document
March 21, 2002 Expert Panel on Funding

Current Operating Structure

The Consortium is a voluntary “confederation” of public and private sector organizations with a common interest in:

- developing, promoting and implementing data standards for public health and health services research through collaboration of state, federal and private sector organizations and
- ensuring that these efforts are appropriately integrated with broader health data standards development efforts.

Consortium membership is open to any organization with a public health focus and with an interest in data standardization for the purposes of health services research and public health. As of March 2002, 35 organizations have joined the Consortium as Steering Committee members. Current member organizations are listed at the end of this document.

The Consortium is governed by a Steering Committee, which is formed by representatives of the member organizations. The Steering Committee provides overall direction for the Consortium, setting priorities and approving all Consortium projects and products. Several Standing and Ad-hoc work groups operate under the Steering Committee. (see Consortium web site (<http://www.cdc.gov/nchs/otheract/phdsc/phdsc.htm>)). The Consortium currently is exploring affiliation with vendor organizations that support standards implementation.

Since the Consortium’s inception in 1999, the National Center for Health Statistics, Centers for Disease Control and Prevention has served as an “informal” secretariat to the Consortium, providing the majority of resources for the following services:

- Organizing and financing the annual meeting of the Steering Committee, including travel support for some member organizations
- Developing and maintaining the Consortium web site and list servs
- Organizing and documenting work group conference calls
- Representation of Consortium at Standards Development Organizations, data content committees (e.g., National Uniform Billing Committee) and other standards venues
- Funding development of the Consortium’s Education Strategy

- Providing seed money for Consortium projects prioritized under the Education Strategy
- Recruiting new members and making presentations at meetings of member organizations

Other components of CDC and DHSS (e.g., Office of the Assistant Secretary for Health, Agency for Healthcare Quality and Research, Substance Abuse and Mental Health Services Administration) have provided resources to support some of these activities, either through reimbursable agreements with NCHS or directly. Several other member organizations represent the Consortium on a regular or occasional basis and chair and direct work groups. Many member organizations serve on these work groups.

Each member organization names a principal and alternate representative to the Steering Committee, but there are no membership dues and there is no separate 501(c)(3) entity that represents the Consortium. Members are expected to bear the cost of participation in the Consortium to the extent possible. Given the non-legal relationship that binds the members of the Consortium together, a critical factor in implementing a business development plan that will attract more resources to support the Consortium's mission is to ensure that the approach and processes that are developed do not strain the relationships that exist across members. Under such circumstances, it is important that the decisions made by the Consortium's Steering Committee and its Business Development and Marketing Work Group (BDMWG) and the processes followed are considered appropriate and equitable. With this in mind, the BDMWG has developed Proposal Selection Criteria and a Project Proposal process, which are documented in a draft Business Development Plan (available upon request). In some cases, Consortium projects are initiated by the Steering Committee and are carried out through Consortium work groups. Other projects may be proposed by individual member organizations or by non-members for one or more of the following levels of engagement:

- General support (e.g., letter of endorsement or support in a grant application)
- Project oversight (through a Consortium work group)
- Direct and active participation in the project's planning and implementation.

Alternative Consortium Operating Structures

Because the Consortium is not a legal entity, it cannot apply for funding from foundations or other potential funders for any of its projects. One approach that has been considered by the Consortium is for a member organization that is itself a 501(c)(3) to take the lead in applying for individual grants on behalf of the Consortium. Another approach would be for several organizational members to apply as a coalition or "mini-consortium" on behalf of the Consortium. In both cases, it would be necessary that selection of projects follow the criteria developed by the BDMWG (assuming adoption by the Steering Committee). In addition, overall oversight of the project would need to be by the Consortium Steering Committee or one of its work groups to assure consistency with Consortium mission and goals and support by all member organizations.

A third approach is to establish a 501(c) (3) organization representing the Consortium that would seek funds for a specific project or set of projects (what might be considered as a 'Doing Business As' Approach). Start-up costs for the organization and resources to apply for funds would need to be borne by one or more of the member organizations until project funding is received.

The Consortium also is interested in identifying and pursuing approaches for getting more money into the overall system (including at the state and local levels) to support public health standards development and implementation. This includes leveraging current strategies for implementing the HIPAA administrative and financial transaction standards and for fostering public health preparedness.

Consortium Member Organizations currently include:

- Academy for Health Services Research and Health Policy (AHSRHP)
- Agency for Healthcare Research and Quality (AHRQ)
- Association of Maternal & Child Health Programs (AMCHP)
- Association of Public Health Laboratories (APHL)
- Association of State and Territorial Health Officials (ASTHO)
- California Cancer Registry (CCR)
- California Office of Statewide Health Planning and Development (OSHPD)
- Centers for Disease Control and Prevention (CDC)
- CDC/National Center for Health Statistics (NCHS)
- Centers for Medicare and Medicaid Services (CMS)
- Council of State and Territorial Epidemiologists (CSTE)
- eHealth Initiative (eHI)
- Health Resources and Services Administration (HRSA)
- Joint Commission on Accreditation of Healthcare Organizations (JCAHO)
- Johns Hopkins School of Public Health
- Massachusetts Division of Health Care Finance and Policy
- Massachusetts Health Data Consortium (MHDC)
- Mental Health Statistics Improvement Program (MHSIP)
- Minnesota Health Data Institute (MHDI)
- National Academy for State Health Policy (NASHP)
- National Association for Public Health Statistics and Information Systems (NAPHSIS)
- National Association of County and City Health Officials (NACCHO)
- National Association of Health Data Organizations (NAHDO)
- National Association of Local Boards of Health (NALBOH)
- National Association of State Alcohol and Drug Abuse Directors (NASADAD)
- National Association of State Medicaid Directors (NASMD)
- Nebraska Health and Human Services System
- New York Statewide Planning and Research Cooperative System (SPARCS)
- Pennsylvania Health Care Cost Containment Council (PHC4)
- Public Health Foundation (PHF)
- State and Territorial Injury Prevention Directors Association (STIPDA)
- Substance Abuse and Mental Health Services Administration (SAMHSA)
Center for Mental Health Services (CMHS)
- Washington State Department of Health
- Wisconsin Bureau of Health Information
- Wisconsin Public Health Data Steering Committee
- Workgroup for the Computerization of Behavioral Health & Human Services Records