

**Public Health Data Standards Consortium
Strategic Planning Meeting
Washington, D.C.
July 17, 2001**

BARRIERS	STRATEGIES/Methods	MESSAGES	PHASE of BARRIER	DATA SYSTEMS	AUDIENCES	PARTNERS
1. Lack of a clear mandate for public health & research; substantial inertia within the status quo	1. Campaign to increase awareness of data standards issues and motivate participation in the public health and research communities by: <ul style="list-style-type: none"> a. presenting at key meetings (see Exhibit 4 pg 31 of report); b. develop educational programs for the audiences (listed in Exhibit 4 pg 31) including the rationale (Appendix D); c. convincing major public health and research associations to make data standards and integration an agenda item at their meetings; d. promoting the Consortium's listservs through presentations and websites; e. monthly broadcast emails about standards issues with a high-level perspective, linking to more detailed information on each topic i.e., privacy. 	1. See AUDIENCES under 1 of this document. See Appendix D in report for rationale.	I	1.	1. Decision-makers: focus on business case for data standards; Collectors: focus on how data standards will improve data flow; Users: focus on the possibilities for enhanced research using data sets.	1. NCHS, ASTHO, the Academy, NEDSS, others...

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2. Lack of funding for standards development	2. See BARRIER/STRATEGY 7. Secure funding by: a. developing a summary of the Ed Strategy report for distribution to funders including Appendix D in report (Rationale for Moving to Data Standards); b. approaching leadership of funding organization (<i>submitting funding proposals</i>); c. disseminating tailored summary versions (specific to the interests of each funding group) of the Rationale for Moving to Data Standards (Appendix D). d. <i>leveraging other initiatives i.e., Medicaid infrastructure building for HIPAA, X12 HCSR, other websites and educational materials.</i>	2. Convince funders of the: a. need for standards development & implementation; b. benefits of data standards for research; c. benefits of common infrastructure to control bioterrorism; d. need for comparable data for performance measures re: HP 2010 and health systems; e. need for activities and the matching resources to go forward.	I	2.	2. Funders: Federal - ASPE, CDC, HRSA (HHS); USDA (for WIC); DOJ (bioterrorism); Other – RWJF; WK Kellogg; CA Healthcare Foundation	2. CDC, NCHS, ASPE
3. Federal & state politics See pg 20 of report. This barrier refers to categorical systems and categorical funding and to legislative and state specific data collection methods.	3.	3.	I	3.	3.	3.
4. Differing levels of readiness See pg 20 of report. This	4.	4.	I	4.	4.	4.

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barrier refers to the lack of coordination between and within states when developing, building and implementing systems.						
5. Lack of awareness in research community around why/how they should be involved	5. See BARRIER/STRATEGY 1 . Post brief summaries for public health staff, health services researchers and the public on what they need to know about national standards development efforts by a. tasking members of the Consortium with developing one-page summaries with easy to read material on the national process from the public health and health services researchers perspective. These should also demonstrate examples of the results of data standardization (i.e., data integration); b. enhancing the Consortium website with these one-page summaries; c. developing a process to update the one-pager products and to monitor their use; d. leveraging the work of other organizations around educational	5. Suggested topics for the educational one-pager educational products are a. What are data standards? b. What are standards setting organizations? c. What is the process for setting standards? d. What standards are relevant to public health and health services research communities currently involved in these efforts? e. How are public health and health services research communities currently involved in these efforts? f. What more can we be doing? g. How can we get involved? See pgs 34-37 of report.	I	5.	5. Decision-makers, collectors, and users	5. ASTHO, the Academy, other accessing and disseminating via web linkages

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	training, which includes the one-pager products.					
6. Need for state, localities and/or programs to change from current systems to broader initiatives	6. See BARRIERS/STRATEGIES 1 and 7. Coordinate educational activities (Public Health Conceptual Data Model and other outreach) with National Electronic Disease Surveillance System (NEDSS) by: a. approaching CDC/NEDSS leadership.	6. States believe that a. integration goes beyond surveillance and should include more such as discharge data; b. failure to coordinate a unified message around data standards risks confusion and frustration at the state and federal levels.	I	6.	6. CDC/NEDSS	6. ASTHO, CSTE, APHL, NACCHO, NCHS, and the Consortium.
7. Difficulty of convincing states & programs not to go it alone	7. Make personal appeals to State Health Officers (SHOs) to get involved by: a. hosting conference calls of small groups of SHOs, mixed with those “on-board” and those who are not, to discuss standardization and integration; b. developing brief, high-level materials describing the benefits of standards and integration for SHOs; c. bringing together SHOs at Consortium meetings and its member’s meetings.	7. See Appendix D in report for rationale. SHOs will respond to: a. strong business cases for data standards tied to improved performance and lower costs; b. the perspective of “being left behind”; c. the perspective of “leadership” satisfaction and professional advancements.	I	7.	7. State Health Officers	7. ASTHO

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8. Fear of increased workload: See pg 21 of report. This barrier refers to DOHs three fears: the inadequate staffing and resources for the increased demand if participating in the SDO process; the potential increased burden on the “keepers” of the data from increased requests of the new and improved data; the inability to address the problems uncovered with the new and improved data due to lack of resources.	8.	8.	I	8.	8.	8.
9. Fear of increased accessibility to data: See pg 21 of report. This barrier refers to SHOs not wanting to share their states’ data in cases of avoiding unwarranted panic i.e., confidentiality issues.	9.	9.	I	9.	9.	9.
10. Upfront costs are high; process is long; benefits too distant: See pg 21 of report. This barrier refers to the low	10.	10.	I	10.	10.	10.

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motivation potential due to attrition of SHOs creating a challenge in data standards given the long-term commitment needed.						
11. Lack of unified national leadership in standards development process for public health	11. Strengthen educational partnerships by: a. clearly articulating how the Consortium’s membership will be impacted by HIPAA <i>and other data standards and systems</i> ; b. convincing ASTHO, NACCHO and the Academy members of the need to prioritize their strategies for data standardization and integration through the use of business cases (Appendix D); c. stressing the risks to ASTHO and NACCHO of not moving to data standards; d. stressing the risks to the Academy members if not involved in the standards development processes i.e., lack of specific data and lack of quality data; e. approaching ASTHO, NACCHO and the Academy for collaboration at the SDOs and other standards	11. See STRATEGIES/Methods . under 11.	II	11.	11. Senior leadership/board members of ASTHO, NACCHO, and the Academy	11. NAHDO, CDC, NEDSS

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	development processes. Reach out to other partners by designating specific Consortium members to develop partnerships with each target organization when the Consortium is ready to implement an educational strategy where the organization could be of help.	Specific to the development of educational materials: a. clearly articulate of how developing/expanding the relationship would be mutually beneficial; b. specify proposals of collaboration, which would include: tasks they would perform, their resources required, and their benefits received from the partnership.			NCHS, CDC, NAHDO, NCVHS, AMIA, WEDI, NAACCR, SHARP, NAPHSIS, MHDC, SPARCS, MHDI, UHIN, others... HCFA, AHRQ, HRSA, APHA, ASPE, NCQA, ANSI HISB, AHIMA, PHF, SDOs, vendors, others.... See Exhibit 3 pg 18.	NCHS, ASTHO, NACCHO, NAHDO, NEDSS, others...
12. Lack of funding for standards development efforts	12. See BARRIERS/STRATEGIES 2, 3, 4, 5, 6 and 7.	12.	II	12.	12.	12.
13. Need for intensive resources & efforts to develop data standards	13. Recruit and train a critical mass of public health representatives by a. prioritizing and selecting the organizations in which the Consortium wants a voice; b. identifying the types of people and organizations that best represent public health and then support them in their participation in SDO activities. These people and organizations should be diverse in systems expertise and communicate among and between	13. Similar messages are reflected in 7 under MESSAGES for SHOs. Other messages for SHOs re: moving to data standards include: a. improved data quality, timeliness, and comparability; b. professional satisfaction. Messages for partners such as ASTHO, the Academy, and the CDC include:	II	13.	13. Decision-makers, collectors, and users	13. ASTHO, the Academy, CDC.

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	<p>communicate among and between their organization, the SDOs and the Consortium;</p> <p>c. focusing on the SHOs for their recommendations of key staff participants;</p> <p>d. drafting of cooperative agreements with federal agencies for funding of participants at standards setting discussions;</p> <p>e. leveraging the work of other organizations around educational training for example, the one-pager products;</p> <p>f. convening the “critical mass of representatives” quarterly (via conference calls) to discuss major issues impacting the public health and health services research communities. The representatives should have reached consensus at their home organizations about information needs that should be addressed by the standard development process;</p> <p>g. posting a list of who is attending which SDO discussions along with their summary of the meeting.</p>	<p>a. clear articulation on how their constituencies will be impacted by HIPAA;</p> <p>b. the potential to gain from the SDO process;</p> <p>c. the potential to lose from lack of participation in the SDO process;</p> <p>d. the role of a common infrastructure in controlling biological threats that cross programmatic and geographic boundaries.</p> <p>Other representatives’ messages include how to participate in the SDO process (see pg 38 of report for general guidelines).</p>				<p>APHA, NCVHS, SHARP, and other regional organizations, NAPHSIS, and state consortia</p>
14. Public health leaders	14. Engage the public health	14.	II	14.	14. Decision-makers,	14. Depends on data

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waiting for private sector to work out bugs in standards development & implementation before investing	community around data standards development for a particular type of data system or data elements by a. choosing a data system that will generate interest and support from state and federal representatives as well as the private healthcare sector; b. leveraging the existing research on standards for this data system; c. forming a workgroup with expertise in the data system; d. developing a business case for the standardization of specific data elements within the data system; e. preparing and presenting to the appropriate SDO.				collectors, and users	system or SDO. The Consortium should partner with a national or state organization that is the most mature in its research and standardization process.
15. Urgent need not yet identified	15. See BARRIER/STRATEGIES 1, 3, 5, 6, 7, and 11.	15.	II	15.	15.	15.
16. Not knowing where/how to start	16. See BARRIER/STRATEGIES 1 and 5. Develop a web-based resource center to track standards development efforts relevant to public health and health services research by a. developing a user-friendly web-site that provides a listing of	16. NEED MESSAGE	III	16.	16. Funders, decision-makers, users, collectors, suppliers and the general public	16. NAHDO, CDC, NCHS, HCFA, WEDI SNIP, SHARP, AMIA, ANSI HISB, NAPHSIS, SDOs,

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	<p>site that provides a listing of standards development efforts, contact information, and links to additional standards information. (a. cont.) This web-site should include a search engine (see general criteria on pg 41-42 of report) and the ability of the user to download documents;</p> <p>b. identifying what standards currently exist, which are relevant to public health, and what processes are already underway for standardization;</p> <p>c. identifying data elements and the appropriate SDO for adding the elements to the SDO code structures.</p> <p>Create a public health implementation guide for selected national standards as they relate to public health by</p> <p>a. developing a practical and consistent guide to help public health respond to national data standards;</p> <p>b. <i>engaging public health and health services researchers in the standards development process</i></p>	<p>The guide should include a detailed explanation of the data standards (see pg 44 of report for general guidelines).</p>			<p>Collectors, users, and suppliers</p>	<p>NAPHSIS, SDOs, others...</p> <p>Depends of standards organization but should include organizations involved in the SDO consensus process.</p>

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	<p><i>promoting a consensus decision-making process.</i> Create an implementation toolbox by</p> <ul style="list-style-type: none"> a. developing documents, which include materials listing the key steps of the standards process in concrete terms; b. including web-based documents and tutorials, distance-based educational seminars, and programs at conferences; c. including seminars where SHO could be trained on the basics of managing data standards, integration, and implementation. This would be funded by the CDC and ASTHO and could be held in conjunction with preplanned (annual) meetings d. leveraging other standards activities i.e., SHARP, GIVES, MHDI, MHDC, and UHIN; e. leveraging others tools such as the AHA survey on hospital members readiness. 	<p>Educational materials would be modular, disseminated via the web, and include</p> <ul style="list-style-type: none"> a. assessments of each states' readiness i.e., AHA survey; b. business case with a slide shows for funding at the state level for SHO and other decision-makers; c. budget templates for estimating resources needed; d. lists of federal and foundation grant-making programs that support data standards implementation, which would include case studies on the "how to..."; e. templates for writing grants such as those at the CDC/NEDSS and the RWJ Turning Point; f. a "make-it-happen" template, which would include the needed number and type of resources, named partners and advisory bodies, processes and strategies; 			<p>Decision-makers (SHO) and collectors (state health department staff)</p>	<p>ASTHO, CDC/NEDSS, NAHDO state data consortia or regional workgroups, vendors, and providers</p>

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		<p>g. sample data maps such as those to help identify trading partners for data exchange and applicable standards for data sets;</p> <p>h. list of recommendations for how to prioritize standards based on national efforts;</p> <p>i. list of alternative models for data integration used by different states (content could be provided from the BARRIER/STRATEGY 17;</p> <p>j. (<i>expanded PHCDM ?</i>);</p> <p>k. list case studies illustrating the processes of states' standards/integration efforts with content from the NAHDO case studies. These case studies could be used to develop manuals for implementing different standards sets;</p> <p>l. list of ways for states to overcome barriers such as staff resistance, poor team efforts, technical knowledge deficits and difficulties, fear of autonomy loss, and differing</p>				

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		readiness levels; m. provision of user friendly data dictionaries and guides for different standards data sets.				
17. Lack of connectivity for standards implementation	17. Develop a web-based resource center to track data integration and standards implementation efforts in public health by a. tracking information specific to implementation efforts about data standards and integration across states and programs, which would include brief descriptions of each entity's activities providing contact information and links to their more detailed information. A search engine would be used for user-friendly access to the state, the program, or the type of data, etc. (see page 49 under "Messages")	17. NEED MESSAGE	III	17.	17. Decision-makers, users, and collectors	17. CDC, NAHDO, NAPHSIS, USHIK, and others...
18. Lack of funding for standards implementation	18. See BARRIERS/STRATEGIES 2, 3, 4, 5, 6 and 7.	18.	III	18.	18.	18.
19. Lack of uniformity in public health's structure across states	19. See BARRIER/STRATEGY 17.	19.	III	19.	19.	19.
20. Lack of coordination across multiple data standards and the integration efforts	20. See BARRIER/STRATEGY 17.	20.	III	20.	20.	20.

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21. Staff/organization resistance: See pg 43 of report. This barrier refers to DOH staff resistance due to their fears of losing historical data, loss of autonomy, increased workload, or loss of job security. Organizational resistance means turf or ownership issues.	21.	21.	III	21.	21.	21.
22. Separation of program and information technology: See pg 43 of report. This barrier refers to the gaps in technical knowledge of the program staff as well as the differences in recruiting and retaining technical experts by each state.	22.	22.	III	22.	22.	22.