A National Agenda for Public Health Informatics

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Views expressed are not necessarily those of CDC or the U.S. Government
American Medical Informatics Association (AMIA) Meeting

• May 15-17, 2001, in Atlanta
• Over 500 attendees
  – Public health
  – Informatics
• Six breakout tracks
  – Frameworks developed prior to the meeting
  – 4 sessions, 1 hour each
  – Plenary presentations from each track
• Recommendations represent views of attendees
1. Funding and Governance

A. Funding

- F-1: Fund information management as part of core public health budget
- F-2: Fund the vision of information, not IT
- F-3: Create diverse funding sources: user fees, taxes, philanthropy, set asides, federal matching
- F-4: Funding must be adequate throughout life cycle: planning, start-up, implementation, maintenance
- F-5: Dedicated funding is needed
1. Funding and Governance

B. Governance and Planning

- F-6: Leadership needed
- F-7: Create planning and management structures that include all stakeholders
- F-8: Assure public health and IT representation in broader systems planning
- F-9: Develop a merged superset of p.h. and informatics planning models (e.g. MAPP)
1. Funding and Governance

C. Business Case

- F-10: Establish business case for continuing investment in information systems
- F-11: Establish business case for public health information architecture
2. Architecture and Infrastructure

A. Infrastructure

- A-1: Provide dedicated Internet access, workstation, and training for all public health personnel & health care providers
- A-2: Provide public health officials with software tools, training, and methods for access to data
2. Architecture and Infrastructure

B. Architecture

- A-3: Develop an implementation plan for the public health information architecture
- A-4: Develop a public health data repository with person-based, integrated data
- A-5: Establish a process to develop an architectural model for the public health data repository
2. Architecture and Infrastructure

C. Architecture Policy

- A-6: Establish procedures for monitoring compliance with audit & evaluation criteria in public health data systems
- A-7: Implement access control measures and computational disclosure control in public health data systems
- A-8: (controversial) Consider establishing a unique personal identifier to facilitate integration of data from multiple sources
2. Architecture and Infrastructure

D. Interface of P.H. and Medical Care

- A-9: Provide effective communication and workflow management capability between p.h. and health care
- A-10: Minimize the impact of public health data collection on health care providers by tapping into existing data streams
3. Standards

A. Development & Implementation Process

- S-1: Increase awareness of, and participation in, current standards development activities within the p.h. workforce at all levels by building on the work of the Public Health Data Standards Consortium
- S-2: Develop & maintain a Web-accessible list of existing standards and standards development groups and activities relevant to p.h.
- S-3: Identify gaps in existing standards and communicate these needs to SDOs
- S-4: Promote consistent use of standards by the U.S. Government, including all of HHS and EPA
3. Standards

B. Development & Enhancement

- S-5: Increase use of CDC’s P. H. Conceptual Data Model & modify/expand it based on user feedback
- S-6: Develop additional standard messages for public health reporting
- S-7: Establish a mechanism for ongoing expansion and maintenance and of the Dwyer tables, which use standardized codes (LOINC and, in some cases, SNOMED) to define the tests and specific results of those tests that should trigger ELR to p.h. agencies
- S-8: Develop model state regulations to promote more consistent reportable disease requirements across the
3. Standards

B. Development & Enhancement (cont.)

- S-9: Develop specific implementation guidelines for creating & transmitting ELR messages using standards and explore mechanisms for promoting & enforcing their use.
- S-10: Continue work to harmonize guideline formats within HL7 and assess their ability to represent population and preventive health guidelines.
- S-11: Create fully-specified database versions of ICD-9-CM and ICD-10-CM to facilitate the development of accurate automated mapping from detailed clinical terminologies to ICD-CM codes for statistical reporting & billing purposes.
4. Research, Evaluation, & Best Practices

- R-1: Agree on a process for developing and disseminating best practices
- R-2: Establish standards for performance at all levels
- R-3: Establish a repository of best practices with mechanisms for discussion, identification of consensus, and endorsement
- R-4: Establish a program to fund demonstration projects showing best practices in privacy protection
4. Research, Evaluation, & Best Practices

- R-5: Evaluation should be explicitly tied to Healthy People 2010
- R-6: Standardize outcome measures
- R-7: Include data quality, economics, transferability, and individual measures in evaluations
- R-8: Evaluate existing programs first
4. Research, Evaluation, & Best Practices

- R-9: Develop a research agenda for PHI
- R-10: Use existing informatics knowledge, techniques, and methods in PHI research
- R-11: Involve multidisciplinary teams in PHI research
- R-12: Include an informatics component in every public health research project proposal and report
- R-13: Provide additional, not reallocated, research funds to study public health informatics
- R-14: Establish and fund a lead research agency for privacy, confidentiality, and security
5. Privacy, Confidentiality, & Security

A. Privacy & Confidentiality Monitoring

- P-1: Create national forum on privacy policy, e.g. National Privacy Advisory Commission (analogous to NBAC)
- P-2: Establish community advisory boards for privacy policy
- P-3: Consider creation of (pilot) public health ethics committees (like hospital ethics committees)
- P-4: Include front-line workers in all public health privacy groups
5. Privacy, Confidentiality, & Security
B. Privacy & Security Policy

• P-5: Develop model wording for public health privacy legislation at all levels
• P-6: Develop regulations and policies that are dynamic and based on risk
• P-7: Develop policies for cross-jurisdictional exchange of data
• P-8: Require all p.h. data systems to have stated purpose, privacy board, confidentiality agreements
• P-9: Develop model security policies
5. Privacy, Confidentiality, & Security

C. Security

- P-10: Adopt HIPAA security requirements as public health security requirements
- P-11: Review security preparedness at all levels of the public health system, specifically addressing denial of service attacks
- P-12: Consider indirect funding options for security, since these investments represent infrastructure that benefits all programs
6. Training/Workforce
A. Educational Programs

- T-1: Establish new and strengthen existing academic programs in PHI
- T-2: Develop a national competency-based continuing education program in PHI
- T-3: Enhance the CDC PHI fellowship program
6. Training/Workforce

B. Curriculum

- T-4: Establish instructional design guidelines for PHI curriculum for the current public health workforce
- T-5: Establish curriculum guidelines for PHI in accredited schools and programs in public health
- T-6: Develop a comprehensive and consistent curriculum about data security, privacy, and confidentiality
- T-7: Consider establishing an ethical/legal/social issues program in PHI analogous to recent p.h. genetics activities
- T-8: Involve appropriate p.h. groups when developing academic and continuing education PHI curricula
- T-9: Within informatics, develop a career track for PHI
6. Training/Workforce
C. Meetings & Organizations

• T-10: Expand the opportunities for public health and informatics folks to come together
• T-11: Strengthen AMIA’s Prevention and Public Health (PPH) Special Interest Group (SIG)
• T-12: NLM, in partnership with AMIA and CDC, should utilize the Regional Medical Library Network to sponsor meetings for public health and informatics outreach throughout the U.S.
6. Training/Workforce

D. Competencies

• T-13: Define public health informatics (PHI)
• T-14: Support CDC and other efforts to develop core competencies in PHI
• T-15: Examine informatics competencies in other health-related fields
• T-16: Adopt the AAMC medical school informatics objectives to PHI
Recommendation Themes

• Coherent governance of PHI activities
  – Include all stakeholders
  – Establish and use standards
  – Formulate and monitor confidentiality policy
  – Identify and disseminate best practices
  – Promote improvement through research

• PHI Training
  – Basic skills for entire workforce
  – Advanced skills for decision-makers
Next Steps

- NCVHS National Health Information Infrastructure (NHII) Workgroup
- Publication (November, 2001):
  - JAMIA (Journal of the American Medical Informatics Association)
  - JPHMP (Journal of Public Health Management and Practice)
- Present recommendations to CSTE, NACCHO, ASTHO, APHA, AMIA, MEDINFO