

White Paper ■

A National Agenda for Public Health Informatics:

Summarized Recommendations from the
2001 AMIA Spring Congress

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Abstract The AMIA 2001 Spring Congress brought together members of the the public health and informatics communities to develop a national agenda for public health informatics. Discussions of funding and governance; architecture and infrastructure; standards and vocabulary; research, evaluation, and best practices; privacy, confidentiality, and security; and training and workforce resulted in 74 recommendations with two key themes—that all stakeholders need to be engaged in coordinated activities related to public health information architecture, standards, confidentiality, best practices, and research; and that informatics training is needed throughout the public health workforce. Implementation of this consensus agenda will help promote progress in the application of information technology to improve public health.

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In 1988, the Institute of Medicine warned that the public health system in the United States was “in disarray.”¹ In response, the public health community, including local, state, and federal agencies as well as other partners, has been working to improve its organizational, workforce, and information infrastructure to create a more coherent system. Although much has been accomplished in all these areas, considerable additional progress is needed to create truly effective and efficient public health information systems.

Such systems could provide, for example, a steady stream of electronic information from a wide variety of sources regarding the health status of every community, to be collected, analyzed, and disseminated.

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Through electronic medical record systems, automated reminders could be presented to clinicians for individually tailored preventive services, immediate feedback on community incidence of disease could be available, and specific surveillance protocols could be activated on demand by public health officials. Furthermore, customized, individualized prevention reminders could be delivered directly to the general public.

However, these potential applications of information technology to public health have yet to be implemented. Although the public health community was an early adopter of computer technology, the technology has been applied almost exclusively in pursuit of narrow, categorical applications that cannot easily be integrated into functional systems that can monitor the health of communities and guide improvement efforts. In addition, the basic computer and telecommunication infrastructure needed to implement effective information systems has been very slow to develop, particularly in small, financially limited local health departments. Public health professionals typically do not have the training and experience necessary to make strategic investment decisions about information technology and effectively implement information systems. As a result,

generally known principles are not uniformly applied, which greatly increases the already high risks involved in these efforts.

Meanwhile, the public health community is facing difficult new challenges, such as bioterrorism,² emerging infections,³ and antibiotic-resistant organisms. Also, the need is increasing for public health to exchange information effectively with other community partners, such as health plan organizations, that are pursuing similar objectives. These trends greatly increase both the need for expanded and more effective use of information technology in public health and the urgency of that need.

Public health informatics, defined as the systematic application of information and computer science and technology to public health practice, research, and learning,⁴ is the emerging discipline that integrates public health and information technology. The development of this field and the dissemination of informatics knowledge and expertise to public health professionals are critical to unlocking the potential of information systems to improve the health of the nation. Major challenges include developing coherent, integrated national public health information systems, increasing integration efforts between public health and clinical care systems, and addressing pervasive concerns about the effects of information technology on confidentiality and privacy.⁵

One unique problem facing public health information systems is that the public health "enterprise" includes multiple local, state, and federal jurisdictions that need to operate in concert. This adds a level of complexity to the development and governance of information systems, beyond that faced even by integrated multi-agency systems in the state or federal context or by private multi-national corporations.

Although still a very new discipline, public health informatics is growing rapidly. The number of publications in the past five years has nearly tripled from the previous period.⁶

Meanwhile, substantial progress has been made in the application of information technology to clinical care through the development of the field of medical informatics over the past several decades. The implementation and refinement of electronic medical record systems and the establishment of integrated academic information management systems represent a vast experience base that is applicable to similar problems in public health.

To address these issues, the AMIA 2001 Spring Congress brought together more than 500 people

from the medical informatics and public health communities to exchange ideas, learn from one another, and develop a consensus national agenda for public health informatics. The recommendations from that conference (Table 1) are summarized here. Additional details about the organization of the meeting and the resultant recommendations have been reported elsewhere.⁷

Funding and Governance

The funding and governance recommendations are based on the premise that health outcomes will be improved and health costs lowered by the provision of accurate and timely individual and aggregated information that supports health decision makers at the consumer, provider, community, and national levels. This vision must be widely discussed and reviewed to ensure support from all stakeholders.

Both public health and clinical information systems must simultaneously serve the information needs of clinical encounters and the community. Data entry and management costs should be minimized and should be consistent with system benefits. Information systems work at the local level; they must ultimately be driven by the needs of local users while conforming to national data interchange standards. Since information system development is an inherently high-risk activity, funders need to share the risks of innovation. To help reduce these risks, expansion of existing systems should be done in a modular fashion.

Recognizing the key importance of information management in public health activities, a consistent dedicated funding stream must be allocated to the development and maintenance of information systems. Such funding should be part of the core budget of every public health agency. Financing incentives must be carefully aligned with the objective of improving access to information to facilitate population health. Information technology investments are valuable only to the extent that they produce results; development of state-of-the-art systems for their own sakes should be avoided. Funds must be available to support the entire information system life cycle, from planning through implementation and maintenance. Also, costs for transition from old to new systems, including training, must be anticipated and budgeted.

Public health partnerships with the community should address issues related to information systems development. Such community participation should facilitate the development of more diverse funding

sources as various participants recognize the direct benefits they can derive from such systems.

Governance is needed to bring together the broad constituency required to facilitate large-scale adoption and implementation of interoperable information systems by public health organizations and users throughout the nation. Such governance need not and should not be autocratic. Rather, an organization is needed that can mediate divergent interests, solicit involvement from and communicate effectively with diverse constituent groups, and provide direction in the coordinated development of public health information systems that support the health improvement efforts of communities.

Some organizations that are crucial to the development of public health systems already exist, such as standards development organizations like HL7, but no single organization is responsible for the orderly and coordinated implementation of information systems to support public health. Thus, many incompatible systems that cannot effectively exchange information have been implemented, and substantial duplication of effort has occurred as different jurisdictions address similar information management needs. Since public health information systems constitute the community dimension of the proposed National Health Information Infrastructure (NHII), the oversight organization for the NHII could be a logical home for such governance of public health system development.

The informatics community should work more closely with public health organizations to ensure that clinical systems meet public health needs and that public health systems provide appropriate feedback to the clinical environment. Also, the considerable experience already gained by the informatics community in the implementation of large-scale clinical systems could be very helpful in the public health setting. Other examples of potential synergies from these two communities working together include the merging of existing informatics and public health planning models into a coherent framework that could be used for public health informatics projects and further work to clarify and define both costs and benefits of public health information systems.

Architecture and Infrastructure

The architecture and infrastructure recommendations reflect the application of clearly established medical informatics “principles” to public health but on a larger scale than medical informatics has yet achieved. The requirements for public health activities are somewhat

broader than those traditionally addressed by medical informatics. For example, public health organizations rely heavily on environmental data relating to water pollution and the distribution of toxic substances in the soil in addition to individual patient-level data.

First, public health informatics must create an information architecture that includes a longitudinal, person-based, integrated data repository. Since one public health use of the repository is clinical care (e.g., treatment and monitoring of patients with tuberculosis), the repository must be similar to those needed for more traditional clinical applications. At the meeting, there was strong group agreement that a common repository of public health data similar to the National Electronic Disease Surveillance System (NEDSS)* model must replace the existing stovepipe, or single application, systems for public health surveillance. However, integrated does not mean centralized—certainly not at the federal level. A distributed model with appropriate levels of personally identified data being held at the state and local level and de-identified data held at the national level may be a viable approach. To achieve a consistent architecture, a well-articulated plan that lays out authority, participants, funding, and processes is necessary.

Second, public health organizations need to ensure that the repositories are created with the functionality, policies, and processes necessary to ensure that data are used only by those who need to know, and that only the amount of personal identifying data needed for a specific, sanctioned public health activity is made available. Medical informatics continues, particularly as the Health Insurance Portability and Accountability Act (HIPAA) requirements become clearer, to work on this same set of issues.

A related architectural policy issue that is very important in medical informatics is the unique personal identifier. Not surprisingly, this was the most controversial issue discussed at the meeting. Standard personal identifiers would make possible the more accurate and efficient collection and analyses of data required to monitor and protect the public health, but participants disagreed about whether such identifiers would increase or decrease risks to privacy. Some participants noted that substantial direct and indirect costs are incurred because of error rates of 12 to 18

* See http://www.cdc.gov/od/hissb/act_int.htm. NEDSS is a CDC program to facilitate the collection, management, transmission, analysis, and dissemination of surveillance data, primarily through the creation of standards. The long-term goal of NEDSS is to develop information systems that gather health data on a real-time basis to detect emerging health problems and monitor trends in the health of communities.

Table 1 ■

Recommendations Developed at Spring AMIA 2001

Funding and governance:

- F-1: Fund information management as part of the core public health budget.
- F-2: Fund the vision of information, not information technology.
- F-3: Create diverse funding sources—user fees, taxes, philanthropy, set asides, federal matching.
- F-4: Allocate adequate funding throughout the information system life cycle—planning, start-up, implementation, and maintenance.
- F-5: Provide dedicated funding for public health information systems.
- F-6: Recognize need for leadership.
- F-7: Create planning and management structures that include all stakeholders.
- F-8: Ensure public health and information technology representation in broader systems planning.
- F-9: Develop a merged superset of public health and informatics planning and evaluation models.
- F-10: Establish the business case for continuing investment in information systems.
- F-11: Establish the business case for the public health information architecture.

Architecture and infrastructure:

- A-1: Provide dedicated Internet access, workstations, and training for all public health personnel and health care providers.
- A-2: Provide public health officials with software tools, training, and methods for access to data.
- 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.
- A-6: Establish procedures for monitoring compliance with audit and 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.
- A-9: Provide effective communication and workflow management capability between public health and health care.
- A-10: Minimize the impact of public health data collection on health care providers by tapping into existing data streams.

Standards and vocabulary:

- S-1: Increase awareness of, and participation in, current standards development activities within the local, state, and federal public health workforce, by building on current work by the Public Health Data Standards Consortium.
- S-2: Develop and maintain a comprehensive Web-accessible list of existing standards and standards development groups and activities relevant to public health, with concise “plain English” explanations and pointers to more comprehensive information.
- S-3: Identify gaps in the coverage of existing standards, and communicate these needs to standards development organizations.
- S-4: Promote consistent use of standards across U.S. federal government agencies, including all HHS agencies and the Environmental Protection Agency.
- S-5: Increase the use of the Public Health Conceptual Data Model of the Centers for Disease Control(CDC), and modify and expand it on the basis of feedback from users.
- S-6: Develop additional standard messages for public health reporting
- S-7: Establish a mechanism for ongoing expansion and maintenance 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 electronic laboratory reporting to public health agencies.
- S-8: Develop model state regulations to promote more consistent reportable disease requirements across the country.
- S-9: Develop specific implementation guidelines for creating and transmitting electronic laboratory report messages using standards and explore mechanisms for promoting or enforcing use of these guidelines.
- S-10: Continue work to harmonize key 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 and billing purposes.

Recommendations (*continued*)

Research, evaluation, and 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.
- R-5: Link evaluation explicitly to the goals of 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.
- R-9: Develop a research agenda for public health informatics (PHI).
- R-10: Use existing informatics knowledge, techniques, and methods in applied 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 PHI.
- R-14: Establish and fund a lead research agency for privacy, confidentiality, and security.

Privacy, confidentiality, and security:

- P-1: Create a national forum on privacy policy, e.g. the National Privacy Advisory Committee (analogous to the National Bioethics Advisory Committee).
- 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.
- 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 public health data systems to have stated purpose, privacy board, and confidentiality agreements.
- P-9: Develop model security policies.
- P-10: Adopt HIPAA security requirements in public health.
- P-11: Review security preparedness at all levels of the public health system, specifically addressing potential denial of service attacks.
- P-12: Consider indirect funding options for security since these investments represent infrastructure that benefits all programs.

Training and workforce:

- 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 Public Health Informatics Fellowship Program.
 - 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 public health genetics initiatives.
 - T-8: Involve appropriate public health groups when developing academic and continuing education PHI curricula.
 - T-9: Develop a career track in PHI within informatics.
 - T-10: Expand the opportunities for public health and informatics professionals to come together.
 - T-11: Strengthen AMIA's Prevention and Public Health Special Interest Group.
 - T-12: Use the National Network of Libraries of Medicine (NN/LM) to arrange meetings for public health and informatics outreach throughout the United States.
 - T-13: Define 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: Adapt the American Association of Medical Colleges (AAMC) medical school informatics objectives to PHI.
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percent in matching data about individuals from multiple sources (W.E. Hammond, personal communication, May 2001); they were divided on the advisability of establishing such identifiers. Any action in this area would have to occur in the States or the Congress. At present, Congress has forbidden the Department of Health and Human Services (HHS) to take any action related to such identifiers. This injunction also covers the National Committee on Vital and Health Statistics (NCVHS), which is an official advisory committee to the Department.

Third, since much of the data that must be stored in a public health data repository is generated by the clinical care process and providers are under increasing pressure to improve productivity, it is imperative that data capture processes be time neutral for providers. Most successful clinical repository groups have relied heavily on linking into existing data sources. In addition, public health activities would benefit from certain data that providers do not routinely capture in a structured or coded fashion today. Medical informatics could take advantage of almost all these data for clinical decision support so that the interests of both groups are exactly aligned. The communication must flow in two directions—data from clinical care to public health organizations and summarized community health perspectives from public health organizations to providers. Because health care providers and public health practitioners work across a large number of organizations, they also need a unifying directory of access information to facilitate communication.

Fourth, to take advantage of this architecture, public health practitioners will need to have appropriate hardware and telecommunication resources along with the training they need to take advantage of these resources. In a 1998 report,⁸ the Centers for Disease Control and Prevention (CDC) found that most local health departments lacked basic information and communication systems and could not communicate reliably to other public health agencies in an emergency. More than half did not have continuous, high-speed Internet access, 20 percent lacked computer capacity, and 70 percent needed training in the use of information technology. Without computers that are capable of supporting contemporary browser-based applications and data analysis tools, public health workers and health care providers will not be able to benefit from any public health applications.

Standards and Vocabulary

The development of electronic public health information systems is critically dependent on the use of data standards—both in the public health sector and among the main external sources of data reported to

public health authorities, including clinical care providers. Unless electronic data are reported in standard formats, it will be prohibitively expensive for public health systems to accept, analyze, and aggregate them correctly.

Participants in the meeting clearly recognized the importance of standards in advancing public health informatics and the critical need to involve more local, state, and federal public health representatives in the standards development process. However, despite a high level of understanding of the importance of standards, relatively few people at the meeting were well informed about existing relevant standards development activities or about the current level of public health participation in these activities. For example, many were unaware of the work of the Public Health Data Standards Consortium (PHDSC)[†], which was established in 1999 by the CDC National Center for Health Statistics (NCHS) with support from the Agency for Healthcare Research and Quality (AHRQ) and encouragement from the NCVHS, to increase public health participation in the development of health data standards. Several actions were recommended to increase awareness of and participation in standards activities in the public health community.

Despite recent positive action within HL7 and other standards organizations to address specific public health needs, there are obvious gaps in the coverage of existing standards as they relate to public health information and transactions. Participants in the meeting agreed that two types of gaps must be identified and filled—gaps in coverage of information needed by the public health system, and gaps in coverage of information needed by those who report to the public health system. In addition to ensuring that direct public health needs are addressed, the public health community has a vested interest in promoting standards that are detailed and comprehensive enough to be useful to, and therefore used by, clinical care providers, laboratories, and other sources of public health data.

Potential gaps identified at the meeting include standard vocabulary for reason for visit, human and animal symptoms and physical findings, risk factors, and preventive measures; unique identifiers for all organizations and providers of interest to public health authorities; standard survey questions; clinical trial descriptions; standards for metadata (e.g., who, what, when, and where) for the source of particular data elements and whole data sets; and standards for additional messages of interest to public health.

[†]See <http://www.cdc.gov/nchs/otheract/phdsc/phdsc.htm>.

Strategies proposed for identifying gaps in existing terminology standards include 1) collecting large representative samples of terminology used in various public health systems and matching this terminology against existing controlled vocabularies, using an approach similar to that used for clinical terminology in the Large-scale Vocabulary Test⁹; and 2) short-term focused efforts to determine the extent to which existing terminologies cover the clinical vocabulary needed to describe key aspects of medical visits, such as chief complaint, symptoms, physical findings, and animal disease manifestations.

Participants recommended that National Library of Medicine (NLM) work with local, state, and federal public health authorities and relevant private sector groups to develop and implement an efficient strategy for identifying gaps in the coverage of public health concepts in existing terminologies. The PHDSC was considered the logical body to organize a review of entities to be covered by HIPAA provider, plan, and employer identifier standards, to help determine what additional entities of interest to the public health community still lack unique identifiers.

In addition to broad recommendations addressing lack of public health awareness and participation in standards organizations, and the general need to identify and fill gaps in coverage, participants recommended several more specific actions. These included 1) expanded use and evaluation of the CDC Public Health Conceptual Data Model,[‡] based on the HL7 Reference Information Model, to facilitate representation of public health data needs to standards development organizations; 2) the development of additional standard messages for public health reporting, including the completion of work already under way on messages for birth and death registration and case definitions for notifiable diseases; 3) ongoing expansion and maintenance 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 electronic laboratory reporting to public health agencies; 4) harmonization of key guideline formats within HL7 and assessment of their ability to represent population and preventive health guidelines; and 5) the creation of fully specified database versions of ICD-9-CM and ICD-10-CM to facilitate accurate automated mapping from detailed clinical terminologies to ICD-CM codes for statistical reporting and billing purposes.

Research, Evaluation, and Best Practices

Even though public health informatics shares much with the disciplines of clinical and bioinformatics, the foci of the public health community on prevention, on communities rather than individuals, on surveillance for disease and injury, and on longitudinal analysis present unique opportunities for research, evaluation, and best practices.

Public health informatics research helps set priorities for resources and ensure that new ideas are adequately tested prior to implementation. A research agenda must be developed that focuses on local, state, and national activities and addresses short- and long-term needs. Specific research agenda items suggested at the meeting are listed in Table 2. The public health informatics research agenda should concentrate on areas that are unique to public health concerns and areas that could have a substantial impact. Whenever possible and appropriate, existing medical informatics knowledge and techniques should be reviewed and used. Multidisciplinary research teams will increase the chances that this complex research will be successful and relevant to public health.

A practical way to foster research and communication is to consistently add an informatics component to the many existing public health research grant applications. Additional research funds should be sought for public health informatics by expanding the entire pool of informatics research funds, rather than splitting it among more grant applicants. Research on privacy, confidentiality, and security issues, which are vital to public health and visible to the general public, is a priority, as is establishing a lead agency to address research in these complex issues.

Evaluation of the public health informatics components of programs involves addressing four key issues:

- How can public health information systems be evaluated?
- How can the effectiveness of public health informatics components be measured?
- How can the effectiveness of data and best practice dissemination be measured?
- What outcome measures are appropriate for evaluation of information systems?

The evaluation framework from Stead et al.¹⁰ was used by the session participants as a starting model to analyze current system development and related public health informatics evaluation methods.

[‡] See <http://www.cdc.gov/od/hissb/docs/PHCDM.htm>.

[§] See http://www.cdc.gov/od/hissb/act_elr.htm.

Table 2 ■

Research Agenda Items in Public Health Informatics

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- Determine the current state of public health informatics (PHI) including infrastructure and workforce.
 - Assess informatics tools for managing temporal, spatial, or multilevel data.
 - Detail standard public health vocabulary used by staff in communities and specific program interventions. Can the vocabulary be standardized to allow for transferability?
 - Study how public health staff uses data. What data are needed for decision making, and how best should that data be delivered?
 - Develop methods of measuring the cost of informatics and the benefit that accrues from its use.
 - Conduct case studies to identify real and perceived privacy issues that arise when public and private data are merged.
 - Explore real time data acquisition and data mining for population data.
 - Determine the health informatics aspects of a “preventive health record” for the community.
 - Study the effect of programs on simulated communities and the utility of this tool for public health planners.
 - Study the ethical issues needed to guide confidentiality policy.
 - Explore the application of methods of statistical disclosure control to public health.
 - Determine the workflow and data needs to inform policy.
 - Determine the minimal level of identifiability needed for each public health task.
 - Determine the security implications of architectures with respect to number of nodes and degree of centralization of data collection and storage.
 - Determine the value and impact of the use of uniform coding and common clinical vocabulary on public health activities.
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Adapting this model and other public health evaluation models to public health informatics applications is an important first step.

Evaluation of public health information systems should be linked to the infrastructure objectives presented in Chapter 23 of *Healthy People 2010*,¹¹ the comprehensive, nationwide health promotion and disease prevention agenda. These include improvements in data and information systems, workforce, public health organizations, resources, and prevention research.

Evaluation will be more useful when standard outcome measures are used, although implementation of such standards is challenging. Evaluation models for public health information systems need to be developed and disseminated. These models should include practical issues for public health, such as data quality, cost, and technology transferability. Comprehensive, standardized, and regular public health informatics evaluation of existing programs should be established. National leadership is crucial to adapt existing informatics evaluation tools and develop standards, templates, tools, and guidelines for public health.

The public health community has long recognized the importance and endorsed the concept of best

practices and is poised to identify and adopt them for informatics activities. The challenge is determining the relevant best practices for public health informatics. The working definition of *best practice* was “a superior method or innovative approach that consistently exceeds the standard level of performance as determined by expert review, evidence of significant improvement vs. the standard approach, consistently superior results, or agreement of multiple sources.” Further consensus development of this definition of best practice, so that it is workable for state, local, and national agencies, should be pursued. Best practices for protecting privacy through adequate security were specifically acknowledged as an urgent need.

Reaching agreement about the process for developing and disseminating best practices is a key step. Each best practice must be both evidence-based and derived from the real-world experience of public health. Key development issues include the following: a range of approaches are necessary to address local, state, and federal perspectives; performance standards or benchmarks based on the Healthy People 2010 infrastructure objectives are essential; and endorsement by professional organizations should be obtained. Once best practices are established, access through a Web-based repository is essential for dissemination. The repository should be interactive, with mechanisms for discussion, identification of consensus building, and endorsement.

¹¹See <http://www.health.gov/healthypeople/document/HTML/Volume2/23PHI.htm>.

Privacy, Confidentiality, and Security

The issues of privacy, confidentiality, and security arise in all aspects of public health informatics. As we create integrated information systems, attention to this area is critical to maintain the confidence of the public. The medical informatics community shares many of these needs, particularly as organizations implement the HIPAA regulations.

The participants recommended creating an entire hierarchy of advisory bodies to address the need for policy development and monitoring. They recommended a national level body to conduct studies and prepare reports on issues occurring at the intersection of health data and privacy, community level advisory boards that would address these issues from local or community perspectives, and possibly even local "public health ethics committees" modeled after hospital ethics committees to address specific situations involving health data and privacy. The participants also felt that "front line public health workers" needed representation at all levels.

Participants identified five specific areas for policy development through these bodies, including developing model wording for public health privacy legislation at all levels; developing regulations and policies that are based on risk to the individual and to communities but adaptable to changing conditions; developing policies for cross-jurisdiction exchange of data; requiring all public health data systems to have a stated purpose, privacy board, and confidentiality agreements; and developing model security policies. In general, participants wanted to create reusable templates or models of regulations, policies, and agreements that would reduce the burden on each individual public health agency.

The recommendations related to security of public health data systems included adopting the HIPAA security requirements, a focused review of security preparedness for all public health systems, and consideration for separate funding of the work necessary to achieve adequate security, since it applies to all public health systems and processes.

Training

A variety of educational and training programs to address public health informatics knowledge and skills are urgently needed by the public health workforce. These programs must be tailored to meet varying needs, ranging from basic information for the entire public health workforce to more specialized,

in-depth management skills for public health managers. Comprehensive public health informatics specialty training is also needed for the development of a cadre of professionals to assume leadership roles in this important area. Specific recommendations include developing and strengthening academic public health informatics programs in accredited schools and programs of public health, developing competency-based continuing education programs, and improving specialty training programs such as the CDC Public Health Informatics Fellowship.

Creation and enhancement of all these programs will be greatly facilitated by the cooperative establishment of competencies and curricula for public health informatics. Development of competencies should begin with a review of the existing definition of public health informatics.⁴ Existing collaborative efforts by CDC and others to develop core competencies for public health informatics should continue and be supported. In addition, public health informatics competencies should be constructed so that other health-related fields could incorporate them as appropriate to facilitate the development of cross-training. In this process of competency development, the Council on Education in Public Health (CEPH), the independent accrediting body for public health schools and programs, should apply the methodology used by the American Association of Medical Colleges (AAMC) for training medical students, to help develop objective criteria for public health informatics.

Instructional design guidelines, including flexible training delivery using the Web and distance learning, short stand-alone modules, and learner selection of content, should be established and used. Public health informatics should be included in the core curricula of all public health programs in an integrated fashion as well as through stand-alone courses. Curricula should include issues related to privacy, confidentiality, and security that are crucial for all public health professionals. Consideration should be given to development of training material and programs dealing with ethical, legal, and social issues in public health informatics. Curriculum development should be done in cooperation with relevant public health and informatics organizations.

Finally, more opportunities are needed for public health and informatics professionals to meet and exchange ideas. The AMIA Prevention and Public Health Special Interest Group should be strengthened and transformed into an official AMIA Working Group that can lead the effort to increase opportunities for interdisciplinary exchange. In addition, the

National Network of Libraries of Medicine should continue to partner with CDC and other public health organizations to offer public health informatics content.

The result of these educational development activities should be the establishment of a career track in public health informatics for public health professionals and ongoing dialogue and exchange between the public health and informatics communities.

Key Themes

In reviewing the recommendations, two overall themes emerge. First, coherent governance over the multitude of currently disconnected public health informatics activities needs to be established. The informatics community needs to participate with the public health community in the creation of mechanisms to oversee the development of the public health information architecture, establish and encourage the use of appropriate standards, formulate and monitor confidentiality guidelines, identify and disseminate best practices, and promote improvement through research and evaluation.

Second, it is clear that the public health workforce must understand the importance of information technology and be trained in both its use and its management. Basic training in modern information management is a necessity for all public health workers, and skills in the management of information technology projects are needed for public health managers, decision makers, and executives. Existing informatics training programs can contribute substantially in this area by incorporating public health material into their curricula.

At present, no organization with the specific responsibility to focus on public health informatics exists. This is to be expected, since these are new issues that have emerged from the application of information technology to public health. However, moving the agenda forward will require the participation of and cooperation from many different organizations and will, therefore, be very challenging.

What are the next steps in the implementation of the recommendations that were developed in this first-ever large-scale collaboration of the public health and informatics communities? First, the recommendations will be presented at upcoming meetings of various public health and informatics organizations, such as the Association of State and Territorial Health Officials (ASTHO), the National Association of County and City Health Officials (NACCHO), the Council of State

and Territorial Epidemiologists (CSTE), and AMIA itself. Presentations are also planned for the Public Health Informatics/Distance Learning Conference, the annual meeting of the American Public Health Association (APHA), and MedInfo 2001.

The elements of the joint strategic plan already developed by the ASTHO and NACCHO information technology committees are closely aligned with the agenda from the AMIA meeting. It is anticipated that both ASTHO and NACCHO will be looking closely at these recommendations to determine how they can actively participate in their implementation.

Summaries of the recommendations, such as the present report, may be helpful in facilitating more widespread dissemination and consideration by policy makers. Although it was not possible at the AMIA meeting to prioritize this agenda, implementation efforts will need to be targeted on the basis of the urgency of particular needs and the opportunities for progress.

Government agencies may consider reviewing and following up on the recommendations from this meeting. In particular, those agencies that were co-sponsors of the AMIA meeting—namely, the Health Resources and Services Administration, NLM, and CDC—are all already involved in public health informatics activities and may find the recommendations from the AMIA meeting useful to their programs and planning processes. Also, the HHS Data Council is responsible for coordinating data and information issues throughout the Department. These recommendations may therefore be of substantial interest to that group. Finally, state and local public health agencies should review these recommendations for potential implementation in their environments.

Of all the existing organizations and committees, the NCVHS is perhaps the most logical group to specifically address these recommendations. Among other activities, it is charged with responsibility for advising the government with respect to the implementation of HIPAA, which includes provisions for establishing standards for administrative transactions for health care and also studying and making recommendations to the HHS Secretary with respect to other health care standards issues such as those for electronic medical records. Although it is staffed and operated by HHS, NCVHS is an official federal advisory committee composed of private sector representatives. This group previously developed the draft NHII framework; public health informatics represents the community dimension of that framework. The recommendations from AMIA were presented to the NHII work group

of NCVHS in late June 2001 and are scheduled for presentation to the NCVHS Subcommittee on Standards and Security in December 2001.

Conclusion

The Spring 2001 AMIA conference successfully brought together public health and informatics professionals in a way that facilitated the development of consensus recommendations that, taken together, constitute a national agenda for public health informatics. A total of 74 recommendations were developed and will be disseminated and discussed throughout the public health and informatics communities. While there was general consensus on many issues, considerable work remains to be done to further clarify many of the most difficult and challenging problems. Meanwhile, both communities stand to gain much by working together to use these recommendations to further advance the application of information technology to improve the health of our communities.

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Appendix

ADDITIONAL CONTRIBUTORS TO THE DEVELOPMENT OF THE RECOMMENDATIONS

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