Towards a National Framework for the Secondary Use of Health Data

Presentation to the National Committee on Vital and Health Statistics (NCVHS)

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By
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AMIA’s position

Secondary Use of Personal Health Information is a Critical Issue for the Widespread Adoption of Health Information Technology

Secondary use of health data can enhance health care experiences for individuals, expand knowledge about disease and appropriate treatments, strengthen understanding about effectiveness and efficiency of health care systems, support public health and security goals, and aid businesses in meeting customers’ needs.

AMIA Expert Panel Meeting

- Meeting Convened April 2006
- White Paper currently available on AMIA web site
- Publication in JAMIA January 2007
- Project Steering Committee
  - Douglas Barton, Meryl Bloomrosen, Don Detmer, W. Ed Hammond, Steve Labkoff, Suzanne Markel-Fox, Charles Safran
- Project Sponsors and Supporters
  - AMIA, GlaxoSmithKline, Lockheed Martin, and Pfizer, GE Healthcare, IBM, Intelligent Medical Objects (IMO), Medstat, and RemedyMD.

Meeting Participants

- **Cheryl Austein-Casnoff**,
  - Director, Office of Health Information Technology, Health Resources and Services Administration
- **Marion J. Ball, EdD**,
  - Fellow, IBM Global Leadership Initiative (GLI), Professor, Johns Hopkins University School of Nursing
- **Douglas Barton**,
  - Director, Enterprise Solutions, Lockheed Martin Integrated Systems & Solutions
- **David Brailer, MD**,
  - former National Coordinator for Health Information Technology, Department of Health and Human Services
- **Laird D. Burnett**,
  - Vice President, Legal & Government Relations, Kaiser Permanente
- **M. Blake Caldwell, MD, MPH**,
  - Senior Advisor, Coordinating Center for Health Information and Service, Centers for Disease Control and Prevention
- **Janet Corrigan, Ph.D, MBA**,
  - President and CEO, National Quality Forum
- **Kelly Cronin**,
  - Director**,** Office of Programs and Coordination , Office of the National Coordinator for Health Information Technology
- **Nancy Davenport-Ennis**,
  - CEO, National Patient Advocate Foundation
- **Don Detmer, MD, MA**,
  - President and CEO, AMIA, Professor of Medical Education, University of Virginia
- **Louis Diamond, MD**,
  - VP and Medical Director, Thomson Medstat
- **Linda L. Dimitropoulos, Ph.D,**
  - Project Director, Health Information Security and Privacy Collaboration (HISPC), RTI International
- **Margo Edmunds, PhD**,
  - Vice President, The Lewin Group, Adjunct Associate Professor, Johns Hopkins Bloomberg School of Public Health
- **Stan Finkelstein, MD**,
  - Senior Research Scientist, Harvard-MIT Division of Health Sciences and Technology, Director of the Harvard MD/MBA
- **Paul M. Gertman, MD**,
  - Chairman, US CareLink

Meeting Participants con’t

- **Melissa M. Goldstein**,
  - Adjunct Assistant Professor of Health Policy, George Washington University, Director, Health Program, The Markle Foundation
- **W. Ed Hammond, PhD,**
  - Professor, Fuqua School of Business, Duke University
- **COL Bart J. Harmon, MD, MPH,**
  - Chief Medical Information Officer, Director of Information Management. TRICARE Management Activity
- **Howard Isenstein,**
  - Vice President, Public Affairs & Quality, Federation of American Hospitals
- **Michael Z. Jones,**
  - Executive Vice President, Sales and Marketing, RemedyMD
- **Robert M. Kolodner, M.D.,**
  - Chief Health Informatics Officer, Veterans Health Administration
- **Steve Labkoff, MD**,
  - Director, Healthcare Informatics, Pfizer, Inc
- **Michael I. Lieberman, MD, MS,**
  - Informatics Director, Practice Solutions, GE Healthcare, Clinical Assistant Professor, Oregon Health & Science University
- **Suzanne Markel-Fox, PhD**,
  - Director, Strategy & Process Development, GlaxoSmithKline
- **Frank Naeymi-Rad PhD, MBA,**
  - CEO, Intelligent Medical Objects, Inc.
- **Dennis S. O’Leary, MD,**
  - President, Joint Commission on Accreditation of Healthcare Organizations
- **Eleanor M. Perfetto, PhD, MS,**
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- **David B. Pryor, MD,**
  - Senior Vice President, Clinical Excellence, Ascension Health

Meeting Participants con’t

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  - Past-Chairman, American Medical Informatics Association, Associate Clinical Professor of Medicine, Harvard Medical School
- **Kevin Tabb, MD,**
  - Chief Quality & Medical Information Officer , Stanford Hospital and Clinics
- **Paul Tang, MD**,
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- **Freda Temple** ,
  - Consultant, Information Management and Editorial Services
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  - Vice President for Public Policy and Government Relations, Joint Commission on Accreditation of Healthcare Organizations
- **P. Jon White, MD**,
  - Health IT Portfolio Manager, Agency for Healthcare Research and Quality
- **David Wye**,
  - Director, Trade & Regulatory Affairs, Lockheed Martin Corporation

Secondary Use of Health Data

Non-direct care use of personal health information including but not limited to analysis, research, quality/safety measurement, public health, payment, provider certification or accreditation, and marketing and other business including strictly commercial activities

Discussion Topics and Issues

- What are the potential benefits and risks regarding the secondary use of health data?
- Who owns the data and who has the right to access the data and for what purposes?
- What are the evolving public trust issues with respect to patient consent for secondary use of data? Do patients have the right to audit or put other constraints on the use of their data even after anonymization?
- In light of serious public health threats such as avian flu, how do we reconcile the public good with the rights of the individual, of health versus privacy considerations?
- What problems may develop as innovative technologies enhance the ability and ease of widespread data sharing and additional commercial use?
- What can be done to address issues arising from inappropriate use and/or exploitation of data sharing?
- What regulations, legislation, and/or policies and procedures are needed to address these issues?

Process

- Conducted an environmental scan and literature review
- Prepared scenarios and presentation topics
  - the consumer; patient safety, quality, and research; public health; and industry
- Convened a meeting April 27 – 28, 2006
- Invited diverse stakeholders and representatives
  - providers
  - technology vendors
  - pharmaceutical companies
  - consulting firms
  - practitioners
  - researchers
  - government agencies
  - consumers
- Facilitated plenary and small group discussions
- Iterative review process for findings and recommendations
- Widespread dissemination of report

Major Findings

- Widespread secondary use of data
- Secondary use has significant value to society
- Patient privacy issues dominate the public trust
- Technological capabilities to merge, link, re-use, and exchange data are outpacing the establishment of policies, procedures, and processes.
- Need for additional attention and leadership at the national and state levels.

Components of a National Framework for Secondary Use of Health Data

- Transparent policies and practices for the secondary use of health data
- Focus on data control rather than data ownership per se
- Consensus on privacy policy and security
- Public awareness
- Comprehensive scope (beginning with a taxonomy)
- National leadership

Recommendation 1

Increase the transparency of data use and public awareness.

Secondary use of health data must be conducted and managed solely through the use of open and transparent processes. Diverse stakeholders should be engaged to assure that these uses are undertaken with full disclosure. Ongoing and future public policy discussions need to explicitly address the secondary use of health data more directly. AMIA is encouraged to share the findings of this meeting with a wide range of stakeholders and through various mechanisms.

Recommendation 2

Focus ongoing discussions on data access, use, and control (not on ownership).

Discussion about the secondary use of health data should focus on access to and control of data for various uses, not on “data ownership” per se. Additional meetings and efforts encompassing a broader constituency must continue to focus on data access and control policies and practices in the context of secondary use of data. The discussions should include considerations of approaches for risk management and mitigation.

Recommendation 3a

Continue discussions on privacy policy and security with regard to the secondary use of health data.

Public and private sector organizations involved in advancing the use of health information should be encouraged to participate in future discussions on the array of complex issues related to privacy and security of the secondary use of health data to develop consensus on pivotal issues. Ongoing discussions should include a wider range and variety of citizen, consumer, and patient stakeholders than were engaged in this conference.

Recommendation 3b

Increase public awareness efforts on the benefits and challenges associated with the secondary use of health data.

A wide range of stakeholders, especially consumer-oriented groups (including patients and their caregivers) should be convened to assure that the public is better informed and educated about the benefits of EHRs and about secondary use of their data. A first step is to identify appropriate organizations and agencies that have a role to play in improving public awareness of the benefits and challenges associated with the secondary use of health data as a means of building public trust in the secondary use of health data.

Recommendation 4a

Create a taxonomy of the secondary use of health data.

A taxonomy of the non-clinical uses of personal health information is needed to address the complex environment surrounding the secondary use of data. The taxonomy is also needed to further clarify the societal, public policy, legal, and technical issues, thereby supporting more productive discussions regarding the data themselves and their potential use.

Recommendation 4b

Address increasingly difficult current and evolving questions related to the secondary use of health data in a comprehensive manner.

These issues include transparency of data, consumer awareness and understanding, technical and technological issues related to identity management and user authentication, commercialization and sale of data, and oversight. Additional discussion and further clarification is needed in defining the range of issues relating to de-identified data. An explicit effort is needed to clarify issues related to data anonymization, working with technical experts in authentication, de-duplication, and identity management.

Recommendation 5

Focus national and state attention on the secondary use of health data.

Additional collaborative efforts need to assure that attention is focused on the issues associated with the secondary use of heath data. The process should lead to the formulation of a clear roadmap to depict and identify the multi-tiered use and re-use of health data, taking into account both current and foreseeable future applications. This is essential to address the complexity that surrounds the secondary use of health data.

Six Principles for a National Framework for Secondary Use of Health Data

- *Transparency* of policies and practices
- *Stewardship* rather than ownership
- *Consensus* on privacy policy and security
- Public *awareness*
- *Comprehensiveness*
- National *leadership*

AMIA Board of Directors Response and Action

- Reviewed the paper and endorsed the panel's recommendations.
- Anticipates committing additional organizational resources to continue to advance the work of the panel and will encourage other organizations to work collaboratively to pursue the recommendations and to continue this important public discourse.
- Plans are underway to convene a second meeting in early 2007.

Questions?

American Medical Informatics Association

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AMIA’s Strategic Agenda

- Through Informatics, transform Healthcare (broadly defined) for Individuals & Populations
  - Equitable, Efficient, Effective,
  - Patient-centered, Timely, Safe
- Transform Informatics from a serious avocation to a formally recognized health profession

AMIA Mission

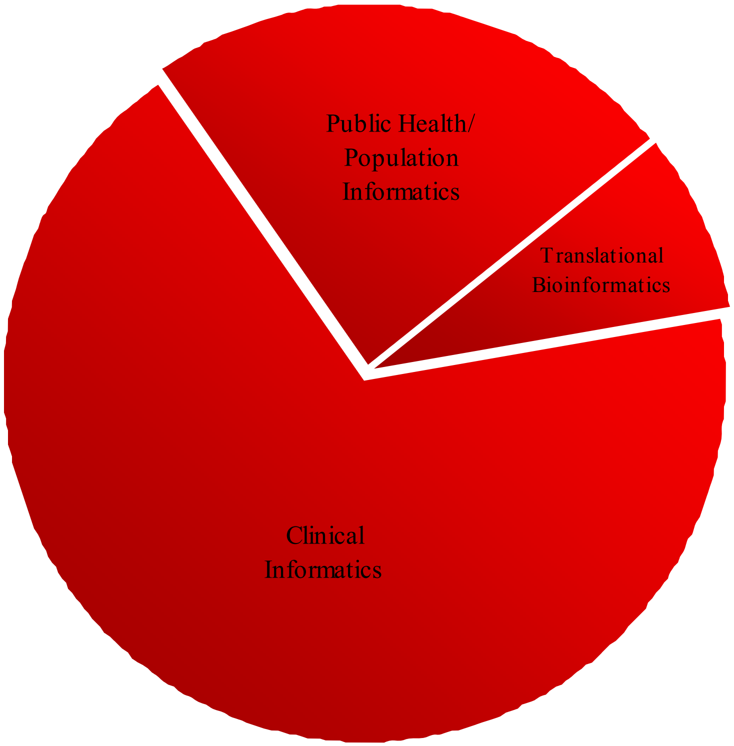
- AMIA advances the informatics profession.
- To this end it advances the use of health communications & information science & technology with the ultimate objective of improving health in clinical care
    - personal health management
    - public health/population
    - education
    - research

AMIA's Domains

- AMIA's programs & initiatives support three major domains of informatics:
- Clinical or health care (including personal health management)
- Public health/population
- Translational research bioinformatics

AMIA Members

- 3,700 members
- Of those indicating an area of interest
  - 68% clinical or health care (including personal health management)
  - 24% public health/population
  - 8% translational bioinformatics



Education Initiatives

- JAMIA
  - Top cited informatics journal (4.3)
    - Editor-in-chief: Randy Miller
- 10x10 Program
  - 276 by end of meeting
  - 9724 to go
- New e-Learning Center
  - Webinars
  - Podcasts
  - Archive of offerings
- Academic Forum & Academic Strategic Leadership Council - Chairmen: Mark Musen & Bill Stead

got EHR?

AMIA 10x10™
10,000 Trained by 2010

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Other AMIA Policy Activities

- Guideposts to the Future – An Agenda for Nursing Informatics (AHRQ)
- Clinical Decision Support Roadmap (ONC)
- Healthcare Terminologies and Classifications: An Action Agenda for the United States (AHIMA)
- Roundtable on integrated PHR (Kaiser, AHRQ, RWJF)
- AHRQ/NRC Policy Paper Series
  - Nursing Informatics in Rural Health
  - Patient Safety and Health Informatics
  - Clinical Workflow Change
  - Small Practice EHR Implementation
- Informatics Research Issues (AMIA/ACMI survey presented at Spring Congress)
- Cosponsor with NCI of Critical Issues in eHealth Research 2006 (Sept 11-12, 2006)
- Participation in Capitol Hill Steering Committee on Telehealth & Healthcare
- Position statements on confidentiality, PHR guidance and workforce

Thank You!

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