AMIA’s 7th Annual Invitational Health Policy Meeting

Health Data Use, Stewardship and Governance: Ongoing Gaps and Challenges

December 12-13, 2012
Washington, D.C.

©
Welcome

Gil Kuperman, MD, PhD
Chair, AMIA Board of Directors
AMIA is...

- A 4,000 member association transforming health care through trusted science, education and practice in biomedical and health informatics.
- An unbiased, authoritative source within the informatics community and the health care industry.
- The bridge for knowledge and collaboration across a continuum, from basic and applied research to the consumer and public health arenas.
Vision: A world where informatics optimizes health and health care
Mission: Promote the science and practice of biomedical informatics
Informatics

- Interdisciplinary field that strives to understand how biomedical and health data can best be managed and manipulated to improve clinical processes and advance scientific knowledge of health and disease
- Domains (rough divisions)
  - Bioinformatics == molecular and cellular processes
  - Imaging informatics == tissues and organs
  - Clinical informatics == individuals / patients
  - Public health informatics == populations / society
- All domains have a spectrum from research to applied
AMIA Board of Directors

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Medical Informatics Certification

• Being advanced by AMIA
• Certification for boarded physicians
  – Beginning in 2013
• Advanced interprofessional certification
  – Under development
AMIA’s Working Groups

- Biomedical Imaging Informatics
- Clinical Decision Support
- Clinical Information Systems
- Clinical Research Informatics
- Consumer Health Informatics
- Education
- Entrepreneurship
- Ethical, Legal and Social Issues
- Evaluation
- Genomics
- Global Health Informatics
- Intensive Care Informatics
- Knowledge Discovery and Data Mining
- Knowledge in Motion
- Knowledge Representation and Semantics
- Natural Language Processing
- Nursing Informatics
- Open Source
- People and Organizational Issues
- Pharmacoinformatics
- Primary Care Informatics
- Public Health Informatics
- Regional Informatics Action
- Student
Opening Remarks and Thanks

Kevin Fickenscher, MD
President and CEO, AMIA
AMIA Wishes to Acknowledge our Meeting Sponsors and Supporters

This meeting was funded in part under grant No. R13 HS 1R13HS021825-01 from the Agency for Healthcare Research and Quality (AHRQ), U.S. Department of Health and Human Services. The opinions expressed in this meeting are those of the participants and do not reflect the official position of AHRQ or the U.S. Department of Health and Human Services.

Astra Zeneca, Deloitte, GE Healthcare, GSK, IBM, Oracle, Philips HealthCare, RTI, and Wolters Kluwer
Health Policy Meeting Steering Committee

- George Hripcsak, Chair
- Patti Brennan, Vice Chair
- Meryl Bloomrosen
- Chris Chute
- Jim Cimino
- Don Detmer
- Margo Edmunds
- Peter J. Embi
- Melissa M. Goldstein
- Ed Hammond

- Gail M. Keenan
- Steve Labkoff
- Shawn Murphy
- Doug Peddicord
- Charlie Safran
- Stuart Speedie
- Howard Strasberg
- Freda Temple
- Adam B. Wilcox
More Thanks

• **Breakout Session Facilitators:** Brian Dixon, Margo Edmunds, Linda Kloss

• **Breakout Session Recorders:** Courtney Hebert, Megan Martin, Devi Mehta, Caryn Roth, Jill DeGraff Thorpe, Freda Temple, Laura Wiley

• **Case Example Contributors:** Leonard D’Avolio, Suzanne Bakken, Patti Brennan, Wendy Chapman, Jim Cimino, Brian Dixon, Brad Doebbeling, Jamie Ferguson, Kathleen Gallagher, Ed Hammond, David Kaelber, Albert Lai, Norman Marks, Patrick Miller, Daniel Pollock, Sally Okun, Marc Overhage, Ashley Peters, Will Rice, Trent Rosenbloom, Tom Scarnecchia, Stuart Speedie, William Tierney, Jim Walker, David Wholley

• **Use Case Contributors:** Steve Labkoff and Charlie Safran
Stakeholders in the Room

- Academicians and Educators
- Clinicians
- Consumer Advocates and Organizations
- Disease Specific Organizations
- Federal Agencies
- HIT Companies
- Lawyers
- Patients
- Payers
- Pharmaceutical Companies
- Policymakers
- Practitioners
- Professional Associations
- Providers
- Regulators
- Specialty Societies
- Standards Organizations
- Students
- Researchers
- Trade Associations
Government Leadership Present

- Agency for Healthcare Research and Quality (AHRQ)
- Centers for Disease Control and Prevention (CDC)
- Centers for Medicare and Medicaid Services (CMS)
- Department of Defense (DoD)
- Health Resources and Services Administration (HRSA)
- Food and Drug Administration (FDA)
- National Institutes of Health (NIH)
- National Institute for Standards and Technology (NIST)
- National Library of Medicine (NLM)
- Office of the National Coordinator for Health IT (ONC)
- Substance Abuse and Mental Health Services Administration (SAMSHA)
- Veterans Health Affairs (VHA)
Purpose of AMIA’s Policy Meetings

• Elevate important health IT and informatics-related policy topics and influence/inform subsequent public policy deliberations and decisions
• Identify and describe areas for further study or research
• Synthesize and disseminate the conference deliberations, findings, and outcomes to inform the policymaking process
AMIA’s Invitational Health Policy Meetings

- **2006**: Toward a National Framework for the Secondary Use of Health Data
- **2007**: Advancing the Framework: Use of Health Data
- **2008**: Informatics, Evidence-based Care, and Research; Implications for National Policy
- **2009**: Anticipating and Addressing Unintended Consequences of HIT and Policy
- **2010**: Future of Health IT Innovation and Informatics
- **2011**: Future State of Clinical Data Capture and Documentation
- **2012**: Health Data Use, Stewardship, and Governance: Ongoing Gaps and Challenges
Framing the 2012 Meeting

- George Hripcsak, MD, MS, Steering Committee Chair; Columbia University
- Patti Brennan, PhD, MSN, Steering Committee Vice Chair; University of Wisconsin-Madison
Overall Purpose of Meeting

• Further a national understanding of health data use in light of new and emerging technology-enabled data sources.

• Promote appropriate, effective data use through recommended policy updates and a research agenda.

• Help develop and advance a nationwide framework for data use that recognizes data as an organizational and enterprise-wide asset and resource with an emphasis on data quality and utility, and acknowledges the significant role of patients, consumers, and caregivers in their health and health care.
2012 Meeting Goals

• Articulate a **vision of** continuous health data use from multiple stakeholder perspectives.

• Review **principles** for continuous health data use and **strategies** to promote widespread dissemination and application of the principles.

• Identify **knowledge gaps and research priorities**.

• Formulate **recommendations** to attain optimal health data use.
2012 Meeting Focus

• Our primary focus is on the use of health data for knowledge and product generation (e.g., research), not the use of data for direct patient care.
Examples of Health Data: Sources and Types

- Data generated and captured in the course of care for an individual person
- Self-reported observations made by an individual
- Sensor-generated signals, e.g., indicating how far a person has walked or their resting sleep patterns
- Data generated across the health lifespan of the individual
- Genomic data
Data Use Terminology for this Meeting

• The term “data use” refers to the “re-use” or “continuous use” of data for purposes other than those for which they were originally collected.
2012 Meeting Assumptions

• Despite challenges, data are currently being used for multiple legitimate purposes beyond direct patient care.

• Technology impacting health data collection and analysis is moving rapidly while public policies are lagging and/or inconsistent.

• It is necessary to examine the roles and responsibilities of all stakeholders (including patients) with regard to data collection, quality, stewardship and governance.

• Health data are viewed as an organizational and system-wide asset and resource.

• Discussions about appropriate data stewardship and governance and data quality issues are more important than ever.

• Data use will only succeed with the buy-in of the public, and AMIA can assist in creating an informative, succinct, balanced public message.
Setting the Stage

• Dynamic financial, technological, political, policy, and social environment
• Unprecedented national attention on exchange and use of data
• Funding and programs help accelerate the adoption of EHRs
• Ongoing research to extract, combine, analyze, synthesize data
• Initiatives to propel mobile health applications
• After decades of ongoing discussions we STILL face significant challenges regarding data use
## HITECH

### October 2012

**EHR Incentive Program**

**Providers Paid Summary**

<table>
<thead>
<tr>
<th>Category</th>
<th>Unique Providers Paid</th>
<th>Unique Providers</th>
<th>Unique Providers Paid</th>
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<td>Medicare Eligible Professionals</td>
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<td>Doctors of Medicine or Osteopathy</td>
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<td>CHIROPRACTOR</td>
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### Active Registrations

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<td>Doctors of Medicine or Osteopathy</td>
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<td>Certified Nurse-Midwives</td>
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<td>Dentists</td>
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<td>Nurse Practitioners</td>
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<td>Physicians Assistants</td>
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<tr>
<td>Medicaid Only</td>
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<td>39,850</td>
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- Active registrations = all eligible professionals who are active registrants that have been fully completed.
Data Ownership

• The notion of “ownership” is inadequate for health information.
• No one has an absolute right to destroy health information.
• There is a complex series of rights and responsibilities relating to health information that should never be trivialized into “ownership.”
mHealth

• Despite data limitations, spatially and temporally referenced mobile phone usage data can provide valuable information on human movement patterns.

• The estimates presented represent the first quantification of the vulnerability of an area to imported malaria, necessary in determining the feasibility of achieving and sustaining elimination.
National Cancer Institute’s SmokefreeTXT Helps Smokers Countdown to Quitting

By Stephen on May 14, 2012

We’ve been seeing a lot recently how tremendously successful text messages are as a tool for helping smokers quit. Text message campaigns are used in cities like New York and Louisville, and research shows how effective it is — sometimes even doubling quit rates.

Now there’s a nationwide smoking cessation service that’s designed for teens and young adults in the United States. The National Cancer Institute is launching SmokefreeTXT, and it takes advantage of the flexibility of mobile to have a two-way, personalized conversation with every user.

**Smoking Cessation Messages over Mobile**

The program works like a 14-day countdown to quitting, followed with six weeks of encouraging messages to help quitters follow through. People can sign up by texting by texting the word QUIT to IQUIT (47846), or from three dedicated websites for adults, teens, and Spanish-speakers.

What’s exciting about SmokefreeTXT is how responsive it is to individual users. In addition to structuring messages around individual quit dates, the program has some neat features that make it more flexible. Several times over the 8-week period, it assesses the smoker’s mood, craving level, and smokefree status with simple text questions, and responds accordingly. If a user reports that they’ve taken up smoking again, the program gives them the option to continue the program as planned or set a new quit date. And if the user reports discouragement or frustration, they’ll get a programmed response that fits the situation. The system even follows up months later to check on the user’s smokefree status and offers any extra help they need.

To find out more about SmokefreeTXT, check out smokefree.gov — or text QUIT to IQUIT (47846) to enroll.

To see our press release about the partnership, click here.

Filed In: All Posts, Blog, government, health, Use Cases
Big Pharma

- Announcement of TransCelerate BioPharma, a new non-profit organization, made up of 10 major global drug firms, focused on accelerating the development of new medicines.
A new Down syndrome patient registry will facilitate contacts and information sharing among families, patients, researchers and parent groups.
Biometrics

• “The receptionist said it was for my own good. The medical center, she said, had recently instituted a biometric patient identification system to protect against identity theft.”
• No longer the province of security services and science fiction films, biometric technology is on the march.
Consumer Data Access and Use
stupidcancer.org

I'm too young for this! foundation

Young adults can and do get cancer.
Here is where they get busy living.

"Being diagnosed with cancer as a young adult has opened my eyes to an entirely new world of others who have gone through exactly what I have. What [2]Jy has provided is the opportunity to connect with my new family."

— Ethan Zohn, Hodgkin's Lymphoma

ABOUT US

Stupid Cancer (aka The I'm Too Young For This! Cancer Foundation, i2y) is a non-profit organization that empowers young adults affected by cancer through innovative and award-winning programs and services. We are the nation's largest support community for this underserved population and serve as a bullhorn for the young adult cancer movement.

A TIME Magazine Best 50 Website, FOX News Top 10 Healthcare Blog and winner of "Most Innovative Use Of Social Media In The World 2011" by the Classy Awards, we support a global network of survivors, caregivers, providers and advocates to ensure that no young adult goes unaware of the age-appropriate resources they are entitled to so they can get busy living.

Our innovative and multi-award-winning programs—such as The Stupid Cancer Show, the OMG! Cancer Summit For Young Adults and the Stupid Cancer Boot Camp—have brought the cause of "cancer under 40" to the national spotlight and rallied a brand new generation of activists to give a much needed voice to our forgotten population. Stupid cancer. Survivors rule.

MISSION, VISION AND CHARTER

Our mission is to empower young adults affected by cancer by:
- building community
- improving quality of life
- providing meaningful survivorship

Our vision is no survivor alone.

Our charter is to ensure that no young adult goes unaware of the support resources they are entitled to.
Welcome to the APCD Council

The APCD Council, formally known as the Regional All-Payer Healthcare Information Council (RAPHIC), is a federation of government, private, non-profit, and academic organizations focused on improving the development and deployment of state-based all-payer claims databases (APCDs). The APCD Council is convened and coordinated by the New Hampshire Institute for Health Policy and Practice (NHHIPP) at the University of New Hampshire (UNH) and the National Association of Health Data Organizations (NAHDO).

RAPHIC was first convened in 2006 by UNH, NHHIPP staff with the goal of engaging future users of the Maine and New Hampshire APCDs in a discussion about multi-state collaboration. Soon after, states across the country joined the group. Currently, there is participation from nearly a dozen states. NAHDO was established in 1986 to promote the uniformity and availability of health care data for cost quality and access purposes. In 2007, NAHDO forged a collaboration with RAPHIC to expand APCD data initiatives beyond the north-east region and to lead fund raising for APCD products and conference support. Together, NAHDO and RAPHIC have been coordinating a multi-state effort to support state APCD initiatives and shape state reporting systems to be capable of supporting a broad range of information needs.

Announcements

- Reminder: APCD Council Bi-Annual Open Forum Call on Monday, November 19 from 2 - 3 PM EST [November 16, 2012]
- APCD Council Presents Award of Recognition to the Centers for Medicare & Medicaid Services [November 9, 2012]
- We are pleased to announce the launch of Colorado’s All-Payer Claims Database. The first round of reports from Colorado’s APCD are now available at www.cvestillhbtics.org. Further, COHIC is hosting a webinar November 10th. 12-1pm MT to recap their November 1st launch event. [November 4, 2012]
- CMS launches flexible and efficient process for states to request Medicare data for research purposes [November 4, 2012]
- NAHDO, APCD Cost Study Summary of Findings [October 16, 2012]

Request for APCD Council Services

Due to an increasing request for services, and to be able to serve you and your organization in a more timely manner, the APCD Council is asking that requests for presentations, informational calls, papers, and other deliverables, be submitted using the button below. Requests are reviewed daily, and the most appropriate member of the APCD Council staff will respond to you.

[Request for Services]
More Social Media

- U.S. Department of Homeland Security (DHS) awarded a contract to enhance its biosurveillance capabilities using social media analytics.
- The social media analytics pilot will manage, link and analyze data from social media networks in real time to better inform and protect the public in the event of a national health emergency.
Communicating with Patients on Health Care Evidence

From an IOM Roundtable:

• “My health data should be used to help improve the care of future patients who might have the same or similar condition.” 89 percent strongly or somewhat agreed with this statement, and just 3 percent strongly disagreed.
Meeting Format, Structure, and Process

• A hands-on, working meeting
• Forward-looking and policy-focused
• Stage-setting plenary sessions
• Facilitated smaller group breakout sessions
• Diverse participants with multiple backgrounds, opinions, and perspectives
• Interactive and open discussions

Meeting Materials
• Briefing Book (agenda, pre-meeting work products)
• AMIA Web Site (pre- and post-meeting information and materials) http://www.amia.org/meetings-and-events/2012-annual-health-policy-invitational-meeting
Day 1 Meeting Agenda

- Welcome and Introductions
- **Plenary Session**: Current Activities and Insights
- **Breakout 1**: Demonstrate Value and Benefits of Data Use and Sharing
- **Plenary Session**: Proposal and a Reactor Panel: Dramatic Reform of National Policy to Support Secure Access to Person-level Data for Quality Life-giving Research
- **Report Outs** from **Breakout 1**
- **Breakout 2**: Identify the Major Future Challenges, Gaps and Barriers to Appropriate and Effective Health Data Use
Day 2 Meeting Agenda

- **Plenary Session**: Considerations for Data Stewardship and Governance
- **Report Outs from Breakout 2**
- **Breakout 3**: The Future: Building on Previous Discussions, Recommend Actions in the Policy, Regulatory, Research and Technological Domains to Propel Action
- **Report Outs from Breakout 3**
- **Plenary Large Group Discussion**: Where Do We Go from Here?
- **Concluding Remarks**
Briefing Book

- Proposed Principles of Data Use
- Definitions of Terms and Terminology
- Matrix Depicting Examples of Current Data Uses
- Matrix Depicting Selected Examples of Federal Agency’s Policies and Programs
- Use Cases
AMIA will compile the information from this meeting to:

- Produce a summary report with policy and research recommendations
- Develop a short range action/research plan that could be pursued by the participants and other stakeholders in order to address the issues
- Disseminate findings and work products through various channels
Proposed Principles for Data Use

1. Appropriate ongoing use of patient health data beyond clinical care of individuals is essential for the nation as a whole and for individuals in order to achieve better health, and safer, better quality of care. Health data should be available and usable on a continuous basis for various purposes.

2. In order to maximize their utility, health data must be made as trustworthy, timely, accurate, accessible, and reliable as possible, and we must be able to track the degree to which health data have attained these properties.

3. Different people, organizations, and stakeholders have varying perceptions and relationships with data that must be honored in order to achieve the compelling and mutual benefits of health data use.

4. There are growing and divergent needs for health data to address efficacy, safety, and effectiveness of health care.
Proposed Principles for Data Use (cont’d)

5. Safeguarding health data from inappropriate use or misuse is essential to assure public support and patient confidence. Those who maintain, aggregate, and use health data, must demonstrate that they are worthy of trust in order to earn and retain the support of patients and the public.

6. There is some risk, however small, of loss or disclosure of confidential patient data. Therefore, in any use of health data, the costs of such loss or disclosure as well as the potential benefits of data use must be carefully assessed.

7. It is not feasible to anticipate all future data sources or data capture technologies and techniques and their potential impact on using data to achieve better health and quality of care. Thus, healthcare system stakeholders must continue to study the impact of use of health data on research and discovery of new knowledge, quality improvement, public health surveillance, and cost reduction, refining these principles as needed, and continually seeking to achieve an appropriate balance between privacy and security and data use.
Overarching Discussion Questions

• Given the ongoing and emerging organizational, technical, technological, and political issues, opportunities and challenges related to the availability, integration, and use of data from multiple sources:
  • What does the future of health data look like and how do we get there?
  • How can we develop and instill a culture throughout the healthcare industry that promotes safe and trustworthy continuous data use?
  • How can we ensure the ongoing accuracy, reliability, and integrity of health data that are collected, reported and increasingly being used nationally and globally for various purposes?
  • With the growing emphasis and acceptance of patients’ role in care, what roles and responsibilities does the patient have regarding data use? Data stewardship?
Breakout Session 1

Demonstrate Value of Data Use

• How can we best illustrate and communicate the value and benefits of data use to patients, providers and other healthcare system stakeholders?
• What are the risks to patients, the U.S. healthcare system and global stakeholders of not using, exchanging, and sharing data?
Breakout Session 2

Identify the Major Future Challenges, Gaps and Barriers to Appropriate, Effective Health Data Use

• In what ways are lack of (or inconsistent) standards/public policies impeding data use?
• Identify the key challenges regarding data quality.
Identify and Recommend Actions in the Policy, Regulatory, Research, and Technological Domains to Propel Action

- What are specific action items and policy recommendations that we can identify?
  - Strategic and collaborative activities?
  - National/state/local public policy efforts?
  - Innovation and research?
  - Training and education?
- What are the responsibilities of various stakeholders and constituencies?
Breakout Sessions: Ground Rules

- The designated facilitators are in charge of the process.
- All ideas and opinions are welcome, valid, and respected.
- Be clear and brief.
- It's OK to disagree. Both/all sides of a position are acceptable. There may be no consensus or solution.
- Everyone participates, no one dominates.
- Maintain an open and positive attitude.
- Be non-defensive about your own ideas.
- Stay focused on meeting themes, purposes, and outputs.
- Ambiguity is OK.
- Avoid side conversations.
- Please stay to the end.
THANK YOU!

Any questions?

Meryl Bloomrosen

meryl@amia.org

301-657-1291
Current Activities and Insights

• Update from the Secondary Data Use SHARP Grant
  • **Christopher G. Chute**, MD, DrPH, Chair of Biomedical Informatics, Mayo Clinic

• EU Data Stewardship Framework
  • **Charles Safran**, MD, MS, Associate Clinical Professor of Medicine, Harvard Medical School

• Overview of Relevant AHRQ Activities
  • **Gurvaneet Randhawa**, MD, MPH, Program Officer, Center for Outcomes and Evidence (COE), Agency for Healthcare Research and Quality
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3. Different people, organizations, and stakeholders have varying perceptions and relationships with data that must be honored in order to achieve the compelling and mutual benefits of health data use.

4. There are growing and divergent needs for health data to address efficacy, safety, and effectiveness of health care.

5. Safeguarding health data from inappropriate use or misuse is essential to assure public support and patient confidence. Those who maintain, aggregate, and use health data, must demonstrate that they are worthy of trust in order to earn and retain the support of patients and the public.
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7. It is not feasible to anticipate all future data sources or data capture technologies and techniques and their potential impact on using data to achieve better health and quality of care. Thus, healthcare system stakeholders must continue to study the impact of use of health data on research and discovery of new knowledge, quality improvement, public health surveillance, and cost reduction, refining these principles as needed, and continually seeking to achieve an appropriate balance between privacy and security and data use.
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- What are the risks to patients, the U.S. healthcare system and global stakeholders of not using, exchanging, and sharing data?
Breakout Session 2

Identify the Major Future Challenges, Gaps and Barriers to Appropriate, Effective Health Data Use

- In what ways are lack of (or inconsistent) standards/public policies impeding data use?
- Identify the key challenges regarding data quality.
Breakout Session 3

Identify and Recommend Actions in the Policy, Regulatory, Research, and Technological Domains to Propel Action

• What are specific action items and policy recommendations that we can identify?
  • Strategic and collaborative activities?
  • National/state/local public policy efforts?
  • Innovation and research?
  • Training and education?
• What are the responsibilities of various stakeholders and constituencies?