Health Data Use, Stewardship, and Governance: Ongoing Gaps and Challenges
7th Annual AMIA Invitational Health Policy Meeting
December 12-13, 2012
Meeting Agenda

Goals
- To further a national understanding of health data use.
- To review principles of data use that can be used to promote an appropriate, effective, informative, and balanced message about the value of health data use.
- To develop an action agenda about how appropriate health data use practices can best be supported by health IT and informatics, including next steps or areas for future research, strategies for implementation and key policy issues.
- To formulate specific recommendations to government, industry, academia, and other stakeholders and identify key steps for moving the action agenda forward.

Day 1 December 12, 2012

7:30 AM       Registration and Continental Breakfast

8:00 AM       Welcome and Opening Remarks: Gil Kuperman, AMIA BOD Chair, and Kevin Fickenscher, AMIA President/CEO

8:10 - 8:30 AM Opening General Session: Setting the Stage. George Hripcsak, Steering Committee Chair and Patti Brennan, Vice Chair

- Framing the Meeting/Meeting Assumptions
- Review of Pre-meeting Work Products (Briefing Book)
- Overview of the Day/Meeting Logistics
- Charge to Meeting Presenters and Participants
8:30 - 9:30 AM  **Plenary Session: Current Activities and Insights**  
- Update from the Secondary Data Use SHARP Grant - Chris Chute  
- EU Data Stewardship Framework - Charlie Safran  
- Overview of Relevant AHRQ Activities - Gurvaneet Randhawa

9:30 - 10:00 AM  **Overview and Goals for Breakout Session 1**  
- Describe Purpose of Proposed Principles of Data Use; Acknowledge Draft Use Cases; Introduce Definitions - Patti Brennan  
- Charge to Meeting Participants - George Hripcsak

10:00 - 10:30 AM  **Break and Participants Travel to Breakout Session 1**

10:30 - 12:30 PM  **Breakout Session 1: Demonstrate Value of Data Use**

12:30PM - 1:00 PM  **Lunch**

1:00 - 2:00 PM  **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**  
- Gil Kuperman, Moderator  
- Don Detmer, Presenter  
- Patti Brennan and Soumitra Sengupta, Reactor Panel

2:00 - 2:30 PM  **Report Outs from Breakout Session 1**

2:30 - 2:45 PM  **Overview and Goals for Breakout Session 2**  
- Identify Impediments to Data Use and Foresee Future Challenges - Peter Embi  
- Charge to Meeting Participants - George Hripcsak

2:45 - 3:00 PM  **Break and Participants Travel to Breakout Session 2**

3:00 - 5:00 PM  **Breakout Session 2: Identify the Major Future Challenges, Gaps and Barriers to Appropriate and Effective Health Data Use**

5:00PM  **Day 1 ADJOURN**

Participants have dinner on their own

6:00 PM  **Steering Committee Dinner/Debrief**
Day 2  December 13, 2012

7:30  Registration and Continental Breakfast

8:00 - 8:30 AM  Opening Plenary Session: George Hripcsak
    - Review of Day One
    - Overview of Day 2/Meeting Logistics

8:30 - 9:30 AM  Plenary Session: Considerations for Data Stewardship and Governance
    - Jane Thorpe
    - Peter Embi

9:30 - 10:00 AM  Report Outs from Breakout Session 2

10:00 - 10:15 AM  Overview and Goals for Breakout Session 3
    - Identify and Recommend Actions in the Policy, Regulatory, Research, and Technological Domains to Propel Action - Margo Edmunds
    - Charge to Meeting Participants - George Hripcsak

10:15 - 10:30 AM  Break and Participants Travel to Breakout Session 3

10:30 AM - 12:00PM  Breakout Session 3: The Future: Building on Previous Discussions, Recommend Actions in the Policy, Regulatory, Research and Technological Domains to Propel Action

12:00 PM - 1:00PM  Reports from Breakout Session 3
    Large Group Discussion: Where Do We Go from Here? - George Hripcsak
        - Identify common themes and potential levers to advance the discussions
        - Formulate key messages for policymakers
        - Propose next steps and action items for stakeholders

1:00 PM  Concluding Remarks, Thank You, and Acknowledgments - George Hripcsak

Steering Committee Debrief