Thursday, July 11, 2019

8:30 AM  Welcome and Introductory Remarks  
David Chu (Institute for Defense Analyses, study committee chair)  
Tyler Kloefkorn (NASEM)  
Sammantha Magsino (NASEM)

8:45  Sponsor Expectations  
Patricia Flatley Brennan (National Library of Medicine)

9:00  The Burdens and Benefits of “Long Tail” Data Sharing  
Adam Ferguson (University of California, San Francisco)

10:00  Break

10:20  Panel Discussion: Researchers’ Perspectives—Managing Risks and Forecasting Costs for Long-Term Data Preservation  
Moderator: Margaret Levenstein (University of Michigan, study committee member)

Panelists:  
Nuno Bandeira (University of California, San Diego)  
Jessie Tenenbaum (Duke University, North Carolina Department of Health and Human Services)  
Gina Tourassi (Oak Ridge National Laboratory)  
Robert Williams (University of Tennessee Health Science Center)

11:40  Panel Discussion: Addressing Data Risks and Their Costs  
Moderator: Michelle Meyer (Geisinger, study committee member)

Panelists:  
Amy O’Hara (Georgetown University)  
Brad Malin (Vanderbilt University)  
Trevor Owens (United States Library of Congress)

12:40 PM  Lunch

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<th>Session 1-A</th>
<th>Session 1-B</th>
<th>Session 1-C</th>
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<tr>
<td>Mechanisms for Forecasting the Costs of Maintained Privacy</td>
<td>Mechanisms for Identifying Risk and Cost Factors of Research Data in the Cloud</td>
<td>Mechanisms for Identifying the Costs of Making Data Truly Findable</td>
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- **Location:** NAS 114
- **Moderator:** Michelle Meyer
- **Rapporteur:** Lars Vilhuber
- **Session 1-A Google Doc**
- **Zoom:** 579 017 678

- **Location:** NAS 118
- **Moderator:** Dave Maier
- **Rapporteur:** Ilkay Altintas
- **Session 1-B Google Doc**
- **Zoom:** 115 483 915

- **Location:** NAS Board Room
- **Moderator:** Bill Stead
- **Rapporteur:** Maggie Levenstein
- **Session 1-C Google Doc**
- **Zoom:** 168 917 218

2:30  **Break**

2:45  **Report on Breakout Sessions**

3:00  **Data**—What’s It Going to Cost and What’s in It for Me?  
*Phil Bourne (University of Virginia)*

4:00  **Precisely Practicing Medicine from 700 Trillion Points of Data**  
*Atul Butte (University of California, San Francisco) [participating remotely]*

4:45  **Open Discussion**—Reflections, Plans for Day 2, Coordination with Study  
*Alexa McCray (Harvard University, study committee member)*

5:15  **Adjourn**
Friday, July 12, 2019

8:30 AM    Introductory Remarks
            Alexa McCray (Harvard University, study committee member)

8:40       Panel Discussion: Incentives, Mechanisms, and Practices for Improved Awareness
            of Cost Consequences in Data Decisions
            Moderator: Lars Vilhuber (Cornell University, study committee member)

Panelists:
John Chodacki (University of California Curation Center, California Digital Library)
Melissa Cragin (San Diego Supercomputer Center)
Wendy Nilsen (National Science Foundation)
Lucy Ofiesh (Center for Open Science)

10:00      Breakout Sessions—Methods to Encourage NIH-funded Researchers to Consider,
            Update, and Track Lifetime Data Costs

<table>
<thead>
<tr>
<th>Session 2-A</th>
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<tr>
<td>Connecting the Dots: Planning Tools for Data Support and Research Computing</td>
<td>Practices for Using Biomedical Data Knowledge Networks for Life-cycle Cost Forecasting and Updating</td>
<td>Incentivizing Researchers to Determine the Costs of Interoperability</td>
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<td>Rapporteur: Chuck Manski</td>
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<td>Zoom: 171 337 802</td>
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11:00      Break

11:15      Report on Breakout Sessions

11:30      Panel Discussion: Researchers’ Perspectives—Reflections and Next Steps
            Moderator: Margaret Levenstein (University of Michigan, study committee member)

Panelists:
Nuno Bandeira (University of California, San Diego)
Jessie Tenenbaum (Duke University, North Carolina Department of Health and Human Services)
Georgia Tourassi (Oak Ridge National Laboratory)
Robert Williams (University of Tennessee Health Science Center)

12:20 PM    Closing Remarks—Themes and Opportunities
            Maryann Martone (University of California, San Diego; study committee member)

12:30      Adjourn