

**WORKSHOP ON COLLECTING, STORING, PROTECTING AND ACCESSING BIOLOGICAL
DATA COLLECTED IN SOCIAL SURVEYS**

November 17-18, 2008

The Keck Center of the National Academies
500 Fifth Street NW
Washington, DC

November 17, 2008 – Room 100

- 8:30 – 8:45am **Welcome and Opening Remarks**
NRC representative
Bob Hauser, Committee chair
Richard Suzman, NIA
- Background and purpose
 - Goals of the workshop
 - Sponsor perspective
- 8:45 – 10:45 **SESSION 1: Overview** **Tab 2**
Session Chair: Bob Hauser, *University of Wisconsin*
- 8:45 – 9:05 **Data Access Versus Confidentiality: Balancing Risks and Benefits**
Ellen Wright Clayton, *Vanderbilt University*
- 9:05 – 9:25 **Where Are We Now? Where Do We Want to Go?**
George Church, *Harvard University*
- 9:25 – 9:45 **Overview of Biobanks and Data Harmonization**
Jennifer Harris, *The Norwegian Institute of Public Health, Oslo,*
Consultant to NIA, NIH
- 9:45 – 10:45 **Discussion**
- 10:45 – 11:00 Break
- 11:00 – 12:30 **SESSION 2: Risks and Rewards of Data Linking** **Tab 3**
Session Chair: Hank Greely, *Stanford University*
- 11:00 – 11:20 **Research Benefits of Linking Biological Data with Social Survey
Data**
Katherine Mullan Harris, *University of North Carolina*
- 11:20 – 11:40 **Legal and Ethical Issues in Using Biological Data and How They
Differ From Social Science Data**
Barbara Koenig, *Mayo Clinic, University of Minnesota*
- 11:40 – 12:30pm **Discussion**
- 12:30 – 1:30 Lunch

1:30 – 3:15	SESSION 3: Storing and Maintaining Biological Data	Tab 4
	Session Chair: Maxine Weinstein, <i>Georgetown University</i>	
1:30 – 1:45	Case Study 1 – PENN Biomarker Core of the Alzheimer's Disease Neuroimaging Initiative	
	Leslie M. Shaw, <i>University of Pennsylvania</i>	
1:45 – 2:00	Case Study 2 – SWAN: Current Practices of Receipt and Storage of Biospecimens	
	Kathi Shea, <i>SeraCare Life Sciences, Inc.</i>	
2:00 – 2:15	Case Study 3 – International Perspectives	
	Bartha Knoppers, <i>University of Montreal</i>	
2:15 – 3:15	Discussion	
3:15 – 3:30	Break	
3:30 – 3:45	SESSION 4: Informed Consent	Tab 5
	Session Chair: Barbara Stanley, <i>Columbia University</i>	
3:45 – 4:00	Current Practices and State of the Art Regarding Informed Consent	
	Holly Taylor, <i>Johns Hopkins University</i>	
4:00 – 4:15	Informed Consent: Recent Developments in Legal and Ethical Requirements for Data Collection and Use	
	Paul Appelbaum, <i>Columbia University</i>	
4:15 – 4:30	The Role of IRBs in Informed Consent.	
	Karen Maschke, <i>The Hastings Center</i>	
4:30 – 5:30	Discussion	
5:30pm	Adjourn	
6:30 – 8:30	Working Dinner	

November 18, 2008 – Room 100

8:30 – 11:00am	SESSION 5: Protecting Data and Confidentiality Session Chair: Bob Wallace, <i>University of Iowa</i>	Tab 6
8:30 – 8:50	America's Changing Concerns about Privacy Alan Westin, <i>Columbia University (Emeritus)</i>	
8:50 – 9:10	Estimating Disclosure Risk Jerry Reiter, <i>Duke University</i>	
9:10 – 9:30	Privacy-Preserving Genomic Data Storage and Mining Murat Kantarcioglu, <i>University of Texas</i>	
9:30 – 9:50	Assessing the Utility of Statistical Methods for Limiting Disclosure Risk: Value of Synthetic Data Sets John Abowd, <i>Cornell University</i>	
9:50 – 11:00	Discussion	
11:00 – 11:15	Break	
11:15 – 12:45	SESSION 6: Accessing and Sharing Data Session Chair: Myron Gutmann, <i>University of Michigan</i>	Tab 7
11:15 – 11:35	Data Licensing Agreements/ Restricted Access Alan Karr, <i>National Institute of Statistical Sciences</i>	
11:35 – 11:55	Repository Issues and Practices MaryFran Sowers, <i>University of Michigan</i>	
11:55 – 12:45	Discussion	
12:45 – 1:45pm	Lunch	
1:45 – 3:00	SESSION 7: Collecting Our Thoughts Session Chair: Bob Hauser, <i>University of Wisconsin</i>	
	Format: Brief comments from the chair followed by a period of general discussion.	
	<ul style="list-style-type: none">• What have we learned?• Remaining questions• Conclusions• Future directions	
3:00pm	Adjourn	

3:15 – 5:30 **CLOSED SESSION (COMMITTEE MEMBERS ONLY) – Room 213**

- Report preparation

6:30 – 8:30 Working Dinner

November 19, 2008

9:00 – 5:30pm **CLOSED SESSION (COMMITTEE MEMBERS ONLY) – Room 208**

- Report preparation [cont.]