Unique Research Communities: Sensitivity to Privacy and Confidentiality, Participants’ Rights, and Communication

Harlem Hospital Center
March 11, 2004

7:30-8:00 Registration & Continental Breakfast

8:00-8:20 Welcome
   - Ruth L. Fischbach, PhD, MPE, Director, Columbia University Center for Bioethics
   - Benjamin Chu, MD, MPH, President, Health & Hospitals Corporation
   - John M. Palmer, PhD, Executive Director, Harlem Hospital Center
   - John T. Herbert, MD, MBA, Senior Associate Dean, Harlem Hospital Center

8:20-9:20 Panel I: Perspectives on Privacy and Confidentiality
   - Andrew K. Joe, MD, Moderator
   - Mindy Thompson Fullilove, MD, Privacy Interests with Diverse Populations
   - Jeffrey P. Davis, Esq., LLM, Practical Realities of HIPAA
   - Lawrence V. Amsel, MD, MPH, Genetic Privacy

9:20-9:50 Group Discussion / Moderator: Andrew K. Joe, MD

9:50-10:05 Break

10:05-10:50 Panel II: Conflicts of Interest and Their Impact on Research
   - John C. M. Brust, MD, Moderator
   - David J. Rothman, PhD, Conflicts of Interest Involving Individual Researchers and the Sponsor
   - David H. Strauss, MD, Conflicts of Interest Involving IRBs
   - Ngina Lythcott, DrPH, Conflicts of Interest Involving Institutions

10:50-11:20 Group Discussion / Moderator: John C. M. Brust, MD

11:20-11:30 Transit

11:30-12:45 Morning Workshops

1. HIPAA
   - Jeffrey P. Davis, Esq., LLM (Primary Facilitator)
   - Heather M. Butts, JD, MPH
   - Stacey B. Mondschein, JD
   - Ronald S. Tikofsky, PhD
2. **Genetic Privacy**  
   Lawrence V. Amsel, MD, MPH (Primary Facilitator)  
   Robert L. Klitzman, MD  
   Elaine L. Larson RN, PhD, FAAN, CIC  
   David H. Strauss, MD  

3. **Informed Consent**  
   George C. Gasparis (Primary Facilitator)  
   John C. M. Brust, MD  
   Maria Cornelio, MA  

4. **Privacy in the Real World: Recruitment and Retention in Inner-City Communities**  
   Al R. Ashford, MD (Primary Facilitator)  
   Wafaa El-Sadr, MD, MPH  
   Vincent E. Hutchinson, MD  

5. **Sensitivity to Community Concerns**  
   Gloria Thomas (Primary Facilitator)  
   Mindy Thompson Fullilove, MD  
   Roberto Lewis-Fernandez, MD  
   Stephen Nicholas, MD  

6. **Conflicts of Interest Facing the Individual Researcher, the Institution, and the IRB Member**  
   Ngina Lythcott, DrPH (Primary Facilitator)  
   Elaine J. Abrams, MD  
   Ruth L. Fischbach, PhD, MPE  
   Jaime S. Rubin, PhD  

12:45-1:00 Transit  
1:00-2:00 Luncheon and Keynote Address:  
Byllye Y. Avery, MEd, *Respect for the Community*  
2:00-2:10 Transit  
2:10-3:10 Panel Presentation III: Inner-City Populations and Communities of Color  
John Corser, MD.................................................................Moderator  
Alan R. Fleischman, MD.....................................................Research with  
Children  
Velvie A. Pogue, MD.............................................................Research in  
Communities of  
Color  
Wafaa El-Sadr, MD, MPH......................................................Research with  
Persons Living with  
HIV/AIDS  
3:10-3:40 Group Discussion / Moderator: John Corser, MD  
3:40-3:50 Break & Transit
3:50-5:05  Afternoon Workshops

1.  **HIPAA**  
   Jeffrey P. Davis, Esq., LLM (Primary Facilitator)  
   Heather M. Butts, JD, MPH  
   Stacey B. Mondschein, JD  
   Ronald S. Tikofsky, PhD

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5:05-5:15  Transit

5:15-5:45  Wrap Up Session: Food for Thought