

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

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5:05-5:15 Transit

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