



**National Institute on Drug Abuse
Division of Epidemiology, Services, and Prevention Research
Crossroads: Sharing Social Environment and Genetic Data**

**Embassy Suites Hotel
Washington, DC**

December 8 – 9, 2008

AGENDA

Monday, December 8, 2008

9:00 – 9:20 a.m.

Welcome & Introductions

Wilson Compton, M.D., M.P.E.

Director

Division of Epidemiology, Services and Prevention Research

National Institute on Drug Abuse

David Shurtleff, Ph.D.

Director

Division of Basic Neuroscience and Behavioral Research

National Institute on Drug Abuse

9:20 – 9:30 a.m.

Workshop Overview

Yonette Thomas, Ph.D.

Chief, Epidemiology Research Branch

Division of Epidemiology, Services and Prevention Research

National Institute on Drug Abuse

9:30 – 10:00 a.m.

**Team Science to Improve Health: Interdisciplinary
Research, Data Infrastructure and Population Impact**

Chris Bachrach

Acting Director, Demographic and Behavioral Sciences Branch

Office of Behavioral and Social Sciences Research

National Institute of Child Health and Human Development

10:00 – 10:15 a.m.

Break

10:15 a.m. – 12:00 p.m.

Session I – The Culture and Benefits of Data Sharing in Interdisciplinary Research

Discussant: Yonette Thomas, Ph.D.
*Chief, Epidemiology Services and Prevention Research
Division of Epidemiology, Services and Prevention Research
National Institute on Drug Abuse*

Speakers:

The Culture of Sharing Genetic Data: Implications for Social Science Data

Laura Bierut, M.D.
*Professor, Department of Psychiatry
Washington University School of Medicine
Washington University in St. Louis*

Using Complex Social Science Datasets in Health Research: Frammingham and the Future

J. Niels Rosenquist, M.D., Ph.D.
*Post-Doctoral Fellow
Department of Health Care Policy
Harvard University*

Genomic and Epidemiologic Models of Data Sharing

Teri Manolio, M.D., Ph.D.
*Senior Advisor to the Director for Population Genomics
Office of Population Genomics
National Human Genome Research Institute*

Data Sharing and the Road to the 'Perfect Study': Some Thoughts About Combining Data From Multiple Sources and Multiple Levels

Sandro Galea, M.D., Ph.D., M.P.H.
*Professor
Center for Social Epidemiology and Population Health
University of Michigan*

12:00 – 1:00 p.m.

Lunch

1:00– 2:15 p.m.

Session II – Exploring the Challenges of Data Sharing: Ethical Considerations

Discussant: Miriam Kelty, Ph.D.
*Consultant
Office of Extramural Affairs
National Institute on Aging*

Speakers:

The Impact of Contextual Data on Disclosure Risks

George Alter, Ph.D.

Associate Director

Inter-University Consortium for Political and Social Research

University of Michigan

No Longer De-Identified: Ethical Considerations of Sharing Genetic Data

Amy McGuire, J.D., Ph.D.

Assistant Professor of Medicine and Medical Ethics

Baylor College of Medicine

Unique Concerns in Sharing Merged Social Environment and Genetics Data

Robert Cook-Deegan, M.D.

Director

Institute for Genome Ethics, Law and Policy

Duke University

2:15 – 4:00 p.m.

Session III – Data Sharing Realities: Experiences from the Field

Discussant: Ty Ridenour, Ph.D., M.P.E.

Associate Professor

Center for Education and Drug Abuse Research

University of Pittsburgh

Speakers:

Causes and Correlates, and National Use Datasets

David Huizinga, Ph.D.

Senior Research Associate

Institute of Behavioral Science

University of Colorado at Boulder

Monitoring the Future: Cross-Sectional and Longitudinal Datasets

Lloyd Johnston, Ph.D.

Distinguished Senior Research Scientist

Institute for Social Research

University of Michigan

(Break: 2:55 – 3:05 p.m.)

Experiences with Merged Datasets (Genetic and Social Science): An Example from Add Health

Brett Haberstick, Ph.D.

Research Associate

Institute for Behavioral Genetics

University of Colorado

Sharing Genetic Data Combined With Phenotypic Data: Experiences from the NGC

John Rice, Ph.D.

Professor of Mathematics in Psychiatry

Washington University School of Medicine

Washington University in St. Louis

4:00 – 5:00 p.m.

Session IV – Merging Paths: National Institute on Drug Abuse Investigator Panel Discussion

Facilitator: Bill Eaton, Ph.D.

Professor & Chair

Department of Mental Health

Bloomberg School of Public Health

Johns Hopkins University

Panel Members:

Jane Costello, Ph.D.

Professor of Medical Psychology

Duke University Medical Center

Nick Ialongo, Ph.D.

Professor

Bloomberg School of Public Health

Johns Hopkins University

Karl Hill, Ph.D.

Research Associate/Professor

Social Development Research Group

University of Washington

Bill Iacono, Ph.D.

Distinguished McKnight University Professor

Department of Psychology

University of Minnesota

Laura Bierut, M.D.

Professor

Washington University School of Medicine

Washington University in St. Louis

Topics for Discussion

- Developing a Data Sharing Plan for Linked Datasets
- IRBs
- Interaction with Communities
- Consent Forms
- Compliance with Data Sharing Policies When Data are Linked
- Benefits of Data Sharing

5:00 p.m.

Adjourn for the Day

Tuesday, December 9, 2008

9:00 – 9:10 a.m.

Introduction to Day 2

Kathy Etz, Ph.D.
*Social Science Analyst, Epidemiology Research Branch
Division of Epidemiology, Services and Prevention Research
National Institute on Drug Abuse*

Marsha Lopez, Ph.D., M.H.S.
*Deputy Branch Chief, Epidemiology Research Branch
Division of Epidemiology, Services and Prevention Research
National Institute on Drug Abuse*

Bethany Griffin Deeds, Ph.D., M.A.
*Health Science Administrator, Epidemiology Research Branch
Division of Epidemiology, Services and Prevention Research
National Institute on Drug Abuse*

9:10 – 10:45 a.m.

**Session V – Data Sharing Infrastructure for
Interdisciplinary Research**

Discussant: Chris Gibbons, M.D., M.P.H.
*Associate Director
Urban Health Institute
Johns Hopkins University*

Speakers:

How to Design Studies While Planning For Data Sharing

Kathleen Mullan Harris, Ph.D.
*James Haar Distinguished Professor
Department of Sociology
University of North Carolina at Chapel Hill*

Data Sharing Requirements: The Analyst's Perspective

Stephanie Lanza, Ph.D.
*Scientific Director and Research Associate
The Methodology Center
The Pennsylvania State University*

**Infrastructure to Protect Human Subjects: New
Methodologies, Remote Access, Imputation, Enclaves**

James McNally, Ph.D.
*Director, Program on Aging
National Archive of Computerized Data on Aging
University of Michigan*

**Harnessing the Potential of Cyber-Infrastructure for
Team Science**

Bradford W. Hesse, Ph.D.

Branch Chief

Health Communication and Informatics Research Branch

Department of Cancer Control and Population Sciences

National Cancer Institute

10:45 – 11:00 a.m.

Break

11:00 a.m. – 12:45 p.m.

Session VI – Identification of Next Steps

Remarks and Summary

James Jackson, Ph.D.

Daniel Katz Distinguished University Professor of Psychology

Institute of Social Research

University of Michigan

Questions for Discussion

- Beyond use of resources and rapidity of answers, what benefits are there to the science of sharing psychosocial and social environment datasets and datasets linking psychosocial/social environment and genetic data? What are the unique benefits for drug abuse research?
- The culture of sharing data varies between genetic researchers and social science researchers. What can researchers from these fields learn from each other regarding data sharing?
- Are the strategies in place to protect human subjects sufficient or must more strategies be developed?
- How can the National Institute on Drug Abuse best facilitate sharing merged social environment/psychosocial and genetic data? You might consider addressing the following areas in your answer:
 - -Infrastructure
 - -Pros/cons to archiving approaches (e.g. small versus large repositories?)
 - -Institutions
 - -IRB's
 - -How sufficient are current human subject protection strategies?
 - -PI's
- What are the next steps for the field in terms of sharing drug abuse data, particularly SED/psychosocial and merged SED/psychosocial and SEG D?

Adjournment?

Ericka Boone 5/28/09 10:27 AM

Comment: What time was the meeting adjourned?