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: Framingham 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 psycosocial/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:
  o -Infrastructure
  o -Pros/cons to archiving approaches (e.g. small versus large repositories?)
  o -Institutions
  o -IRB’s
  o -How sufficient are current human subject protection strategies?
  o -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 SEGD?

Comment: What time was the meeting adjourned?