



# Draft Agenda: Ethical, Legal, and Social Implications of Gene-Environment Interaction Research

January 11-12, 2022 (All times in EST)

## Day One

### 11:00 am: Welcome and Charge

#### *Introductory Remarks*

[Rick Woychik](#), Ph.D., Director, National Institute of Environmental Health Sciences  
[Eric Green](#), Ph.D., Director, National Human Genome Research Institute

#### *Charge and Goals of Meeting*

[Dave Kaufman](#), Ph.D., Program Director, NHGRI  
[Kim McAllister](#), Ph.D., Program Director, NIEHS

### 11:45 am: Communicating Risks and Findings from GxE Research

Explaining genomic risks of disease can be difficult and explaining exposure risks may be even harder. Issues will arise in the communication, interpretation, and use of gene-environment interaction (GxE) research results in a wide variety of settings including public health, public policy, and healthcare. How do we communicate both individual and community level risks? How might we define actionability of GxE results that can be addressed at levels from individual care to public policy and exposure mitigation? Considering that in complex diseases, neither genomic nor environmental factors alone tend to be causal, how does one approach the uncertainty of GxE research findings? Can we ensure that risk information accounts for social and systemic determinants of health? What plans for communicating findings should be incorporated at the outset of GxE studies?

#### *Presentations*

[Julia Brody](#), Ph.D., Silent Spring Institute, “What Can GXE Studies Learn from Personalized Report-Back for Chemical Exposures?”  
[S. Malia Fullerton](#), D.Phil., University of Washington Medicine, “Communicating Results in GxE Research: Lessons from Genomics Return of Results Policies and Practice”

#### *Discussion*

Moderator: [Dana Dolinoy](#), Ph.D., University of Michigan School of Public Health  
Additional Panelists: [Jennifer Fairman](#), M.A., Johns Hopkins University School of Medicine, [Katrina Korfmacher](#), Ph.D., University of Rochester Medical Center, and [Ambroise Wonkam](#), M.D., Ph.D., University of Cape Town, South Africa



1:30 pm: Break

2:00 pm: Community Research

How do we engage communities as true partners setting research agendas, governing data, and sharing in the risks and benefits of the work, to build gene-environment research portfolios most relevant to community concerns and interests? Looking forward, are studies that combine genetic and environmental data likely to create unique barriers, risks, and/or opportunities for communities? Can we anticipate and plan for novel uses of data and research results by the communities in a study? What lessons from research with indigenous communities and other community-engaged GxE research can NIH build upon?

*Presentations*

[Johnnye Lewis](#), Ph.D., University of New Mexico, “When Place Identifies People. Can Causes of Disparities Be Identified Without Creating New Risks? Data Sovereignty and Privacy in the Age of Big Data”

[Ana Navas-Acien](#), M.D., Ph.D., Columbia University, “Environmental Justice and GxE Research: Experiences from Working with Indigenous Communities”

*Discussion*

Moderator: [Holly Peay](#), Ph.D., RTI International

Additional Panelists: [Meg Doerr](#), M.S., Sage Bionetworks, [Vanessa Hiratsuka](#), Ph.D., University of Alaska Anchorage, and [Justin Lund](#), Ph.D., University of Oklahoma

3:45 pm: Conclusions and Thoughts for Day Two

Dave Kaufman and Kim McAllister

4:00 pm: Optional Happy Hour

All Attendees



## Day Two

11:00 am: Overview of Day Two

Dave Kaufman and Kim McAllister

11:15 am: Social and Environmental Justice

It has been apparent to many for a long time and to all in the wake of the COVID-19 pandemic that we must broaden our view of how we will come to understand complex human disease development. An individual's genomic sequence and measures of their individual environmental exposure levels (and GxE interactions) are necessary but insufficient knowledge for understanding common complex disease risk. What frameworks are needed to ensure that going forward, GxE research accounts for and explains exposures to social determinants of health, structural racism, and the uneven distribution of healthcare resources and environmental hazards? How can researchers ensure that findings about the biological effects of geographical place, neighborhood, and genetic variants cease being equated with the social construct of race? As we support new teams of researchers, what disciplines should be included to address issues of health disparities? What new social justice issues may be raised by GxE research, and what roles might the research play in addressing them?

### *Presentations*

[Janet Shim](#), Ph.D., University of California, San Francisco, "Justice-Centered Frameworks and Considerations for GxE Research."

[Karriem Watson](#), D.H.Sc., All of Us Research Program, "Diversity, Equity and Inclusion, and Intersectionality in Genomics Research"

### *Discussion*

Moderator: [Laura Senier](#), Ph.D., Northeastern University

Additional Panelists: [Ruby Mendenhall](#), Ph.D. University of Illinois Urbana-Champaign, [Rachel Morello-Frosch](#), Ph.D., UC Berkeley School of Public Health, and [Consuelo Wilkins](#), M.D., Vanderbilt University Medical Center

1:00 pm: Break

1:30 pm: Privacy Issues and Discrimination

As large studies combine genetic, environmental, social, and geospatial information, these highly dimensional datasets will create new opportunities for re-identification of individuals and groups. New combinations of data types may create novel information not previously known about individuals and communities. As researchers attach meaning about disease and environmental risk to the data, additional stigma and potential for discrimination may arise. Combinations of technical, legal, and ethical solutions to protect against some genetic harms



currently exist but the extent that protections cover [genetic] susceptibility to environmental exposures is poorly understood. What risks to individuals and communities should be foreseen and addressed as researchers combine many types of genomic and environmental data with broad research consent? Are there policy gaps in protection that warrant consideration?

*Presentations*

[Cole Brokamp](#), Ph.D., Cincinnati Children’s Hospital Medical Center, “Challenges and Solutions for Private and Reproducible Environmental Exposure Assessment at Scale”

[Anya Prince](#), J.D., University of Iowa, “Current Legal Protections and Gaps in Genetic Antidiscrimination Law”

*Discussion*

Moderator: [Charmaine Royal](#), Ph.D., Duke University

Additional Panelists: [Marta Jankowska](#), Ph.D., City of Hope, [Gary Marchant](#), J.D., Ph.D., Arizona State University College of Law, and [Deven McGraw](#), J.D., Invitae

3:15 pm: Break

3:30 pm: Final Discussion  
All Attendees

4 pm: Recommendations and Next Steps  
[Lisa Chadwick](#), Ph.D., Program Director, NHGRI  
[Charlisse Caga-anan](#), Program Director, NCI