COLUMBIA PRECISION MEDICINE INITIATIVE

PRECISION MEDICINE & SOCIETY
SCHOLARS' DAY

FEBRUARY 17, 2023

Columbia University, Morningside Campus
Alfred Lerner Hall, Room 555
2920 Broadway, New York, NY 10027
1:00 pm - 3:30 pm

COLUMBIA | PRECISION MEDICINE

Schedule

PRECISION MEDICINE & SOCIETY: SCHOLARS' DAY

Columbia University, New York

May 11, 2022

1:00 pm	**Opening Remarks** Paul Appelbaum, MD Rebecca Jordan-Young, PhD
1:20 pm	**Alexander Borsa, PhD candidate**
1:45 pm	**Wendy Chung, MD, PhD**
2:10 pm	**Lucas Matthews, PhD**
2:35 pm	**Rafael Yuste, MD, PhD**
3:00 pm	**Larry Au, PhD**
3:30 pm	**Networking Reception**

Welcome to Precision Medicine & Society Scholars' Day at Columbia University. Today's conference will highlight the work of junior and senior scholars across the University who received funding for their pilot projects from the Precision Medicine & Society Program.

The Precision Medicine & Society Program is an integral part of Columbia's Precision Medicine Initiative. This University-wide collaboration was created to support academic discussion and research about the interplay between the biomedical advances of precision medicine and the social sciences, humanities, law, and business. It brings together biomedical and public health researchers, clinicians, and bioethicists working at our Medical Center with social scientists, legal scholars, and humanists in the Faculty of Arts and Sciences, the Law and Business Schools, and Barnard College.

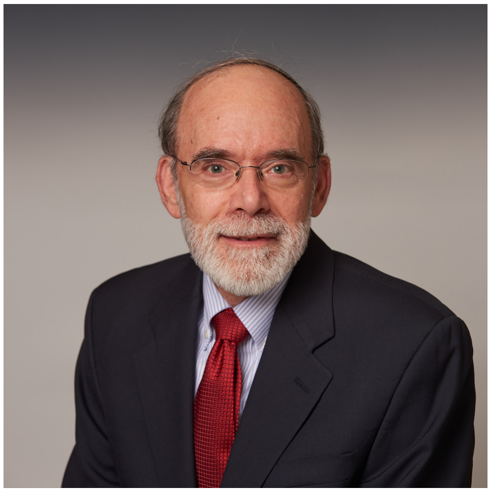
This year's PM&S Scholars' presentations will address topics ranging from the impacts of genetic essentialism and genetic testing on sexual orientation to newborn genomic screening, polygenic predictions of educational attainment, the privacy of data collected by new neurotechnologies, and the implementation of precision medicine in China. The scope of our scholars' interests demonstrates the potentially profound impact of precision medicine on a diverse array of societal concerns.

We believe that Columbia University is ideally positioned to lead this conversation, as it was among the first academic institutions to create a program dedicated to precision medicine and society. Our thanks to President Lee C. Bollinger, the Columbia Precision Medicine Initiative, and its director, Tom Maniatis, for supporting the Precision Medicine & Society Program and making possible this fourth annual conference. We are also grateful to Roy Vagelos for his vision and support for precision medicine at Columbia.

Paul S. Appelbaum, MD, Elizabeth K. Dollard Professor of Psychiatry, Medicine and Law, Columbia University Irving Medical Center

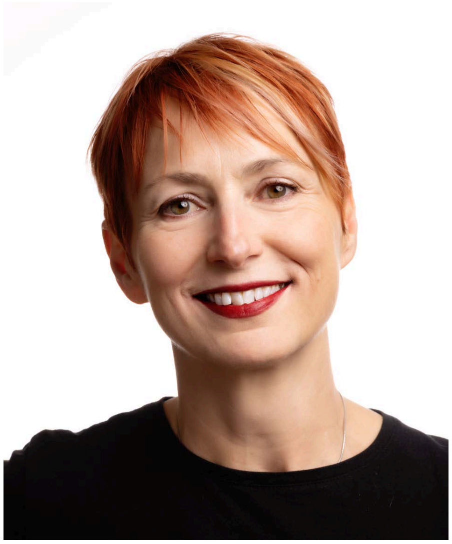
Rebecca Jordan-Young, PhD, Ann Whitney Olin Professor and Chair, Department of Women's, Gender and Sexuality Studies, Barnard College

Co-Directors of the Columbia Precision Medicine & Society Program

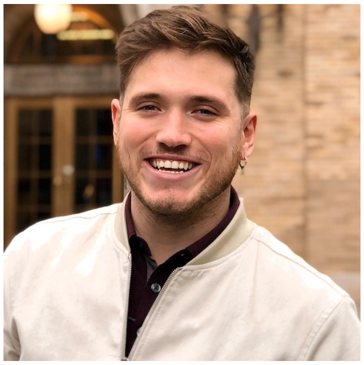


PAUL S. APPELBAUM, MD, co-chair of the Precision Medicine & Society Steering Committee, is the Elizabeth K. Dollard Professor of Psychiatry, Medicine, and Law, and Director, Center for Law, Ethics, and Psychiatry, Department of Psychiatry, Columbia University. He directs Columbia's Center for Research on Ethical, Legal, & Social Implications of Psychiatric, Neurologic, & Behavioral Genetics. The author of many articles and books on law and ethics in clinical practice and research, Dr. Appelbaum is a Past President of the American Psychiatric Association and chairs the DSM Steering Committee. A graduate of Columbia College and Harvard Medical School, he has been elected to the National Academy of Medicine.

REBECCA JORDAN-YOUNG, Ph.D, co-chair of the Precision Medicine & Society Steering Committee, is Ann Whitney Olin Professor and Chair of Women's, Gender, and Sexuality Studies at Barnard College. Dr. Jordan-Young is an interdisciplinary scientist and science studies scholar who explores reciprocal relations between science and the social hierarchies of gender, sexuality, class, and race. The author of two award-winning books and many articles in a wide range of science and humanities journals, her work has been supported by the John Simon Guggenheim Foundation, the American Council of Learned Societies, the Brocher Foundation, the NSF, the NIH, the Social Science Research Council, and others.



Alexander Borsa, PhD candidate



Alex Borsa is a 4th year doctoral student in Sociomedical Sciences, with affiliations in the Department of Sociology and the Institute for Studies of Sexuality and Gender. He is also a member of the GenderSci Lab at Harvard University. Alex studies emerging issues related to gender, sexuality, and health, including the rise of genetics research on sexuality and the financialization of reproductive healthcare. Alex has served on the NYC HIV Planning group, and was involved in the NYC Mpox response this past summer.

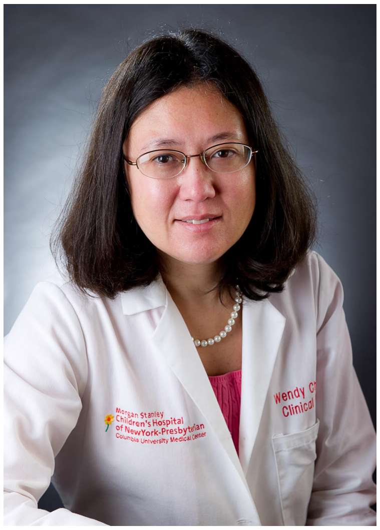
Talk Title: The Impacts of Genetic Essentialism and Genetic Testing on Sexual Identity Formation

Abstract: Population-level genomic data are increasingly used to study genetic correlates of sexual behavior. Given the proliferation of new genetic services in clinical settings and consumer markets, it is likely that applications of behavioral genetics and sociogenomics research on sexuality will become widely available to patients and consumers, impacting sexual subjectivities and understandings of sexuality. To explore the role of genetic essentialism in sexual identity formation and how emerging genetic research may influence lay theories of sexuality, we conducted 50 semi-structured, in-depth interviews with participants of diverse genders and sexualities based in New York City. Interviews focused on participants' sexual identities and histories, as well as their understandings of the relationship between genetics and sexuality.

The interviews also involved an experimental probe, before which participants were presented with information about recent research on genetics and sexuality, including the production of a direct-to-consumer app that purported to test for sexual orientation using results from a commercial DNA test. They were then asked to respond to scenarios revealed to be false after the interview where hypothetical others received genetic test results about their own sexuality. Participants across identities presented a wide range of causal theories about the origins of sexuality and its possible relationship to genetics, as well as a wide range of ethical appraisals about sexual genetics research and testing. Many individuals articulated multiple causal stories and ethical assessments over the course of a single interview. We also found that most participants claimed that they would take a sexual genetics test if offered, including those who were skeptical about the trustworthiness, robustness, or ethics of behavioral genetics research and testing. Many participants across sexualities viewed test results whether in scenarios about hypothetical others, or themselves in the future as an opportunity for sexual introspection, exploration, and self-discovery.

Our results align with sociological findings that essentialist ideas are a flexible and strategic explanatory device, and extend those findings to sexual identities. These results also call into question the research ethics of invoking the approval of sexual and gender minority stakeholders to justify behavioral genetic and sociogenomic research on sexuality. Lastly, our results suggest that individuals who accept or seek out genetic sexual tests may be engaged in what we call genetic play, in which curiosity, erotic practice, and genetic science intermingle to change sexual subjectivities and self-understandings.

Wendy Chung, MD, PhD

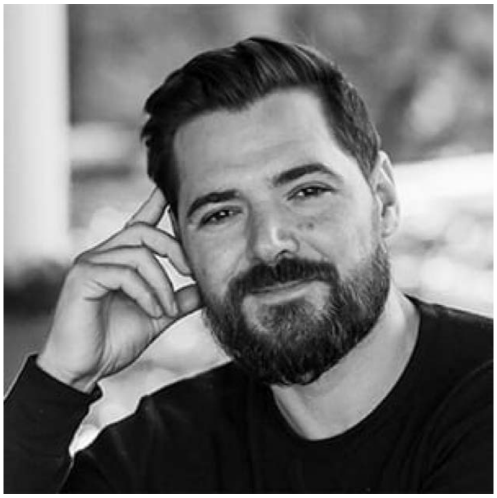


Wendy Chung, M.D., Ph.D. is a clinical and molecular geneticist and the Kennedy Family Professor of Pediatrics in Medicine and Director of Clinical Genetics at Columbia University. Dr. Chung directs NIH funded research programs in human genetics of pulmonary hypertension, breast cancer, obesity, diabetes, autism, birth defects including congenital diaphragmatic hernia and congenital heart disease. She is a national leader in the ethical, legal, and social implications of genomics. She leads the Precision Medicine Resource in the Irving Institute and the National Organization of Rare Disorders Center of Excellence at Columbia University. She was the recipient of the NY Academy of Medicine Medal for Distinguished Contributions in Biomedical Science, the Rare Impact Award from the National Organization of Rare Disorders, and is a member of the National Academy of Medicine and the American Academy of Physicians.

Talk title: GUARDIAN: Genomic Uniform screening Against Rare Disease in All Newborns

Abstract: GUARDIAN represents a new platform for newborn screening using genome sequencing and provide equity in genomic medicine for the next generation. We will review/ describe the study and experience with the first 1000 newborns.

Lucas J. Matthews, PhD

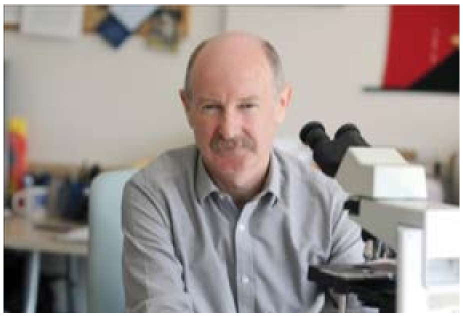


Lucas J. Matthews is an assistant professor of bioethics in the department of Psychiatry and Columbia University, and a presidential scholar at The Hastings Center. He received a PhD in philosophy from the University of Utah where he studied conceptual issues in evolutionary biology. He completed a three-year postdoctoral fellowship in human behavior genetics at the University of Virginia, where he examined methodological problems related to genomic research on intelligence. He later completed a two-year postdoctoral fellowship in bioethics at The Hastings Center and the Columbia University Center for Research on Ethical, Legal and Social Implications of Psychiatric, Neurolgic and Behavoral Genetics. His latest research examines ethical, psychosocial, and political implications of the development and direct-to-consumer availability of genetic testing for educational outcomes, such as intelligence, math ability, reading ability, and educational attainment. Google Scholar Profile

Talk Title: Intersectionalities in a Sociogenomic World: Does polygenic prediction of education impact public perceptions of educational, criminal, and life-long trajectories?

Abstract: Recent developments in human behavior genetics hold the potential to impact attitudes and beliefs about educational achievement, criminal behavior, and more generally life-long trajectories of children in the United States. As traditional twin and family studies are slowly displaced by genome-wide association studies (GWAS), geneticists are now able to construct DNA-based genetic predictors for a variety of social behaviors and outcomes, including educational attainment (EA), income, and behavior problems. Placing any individual sample of DNA on a spectrum from low to high, a polygenic score for educational attainment (EA-PGS) permits what is often interpreted as a person’s “genetic risk” for education. This is a burgeoning focus of behavior genetic research, with one recent study further identifying an association between low EA-PGS and criminal behavior. These recent developments in genomic prediction of social outcomes raise significant ethical, legal, and social implications (ELSI) challenges that need to be examined, especially as they are inseparable from a long and disturbing history of efforts to use behavior genetics to justify racist, classist, and ableist ideologies and policies. Although the sordid history of race, (dis)ability, socioeconomic status (SES), and genetics is well-documented, the likely interaction between polygenic prediction of education and public perceptions of race, SES, disability, criminal behavior, and school achievement remains unknown. This project seeks to advance crucial ELSI literature on how EA-PGS intersect with conceptualizations of (dis)ability, SES, race, and racial difference.

Rafael Yuste, MD, PhD



Rafael Yuste, a neuroscientist, is Professor of Biological Sciences at Columbia University in New York. He studies the function and pathology of the cerebral cortex, using optical methods to measure and modify the activity of its neural circuits.

Yuste grew up in Madrid, Spain and obtained his MD at the Universidad Autonoma in Madrid. After working in Sydney Brenner's laboratory at the Medical Research Council in Cambridge, UK, he was a Ph.D. student with Larry Katz in Torsten Wiesel’s laboratory at Rockefeller University in New York, and postdoctoral student of David Tank at Bell Laboratories in New Jersey. He joined Columbia in 1996 and is currently director of its Neurotechnology Center and co-director of its Kavli Institute for Brain Circuits.

In 2011 Yuste led a small group of researchers who proposed the Brain Activity Map, precursor to the US BRAIN Initiative, and in 2016 he helped coordinate the launch of an International BRAIN Initiative. In 2017, he also led the “Morningside” group of 25 researchers and clinicians who proposed novel human rights (“Neurorights”) to protect citizens from potential abuses from neurotechnologies and AI.

Yuste’s is a member of Spain’s Royal Academies of Medicine and of Science and was a member of the Howard Hughes Medical Institute. His scientific contributions have been recognized by awards from the Mayor of New York City, the US Society for Neuroscience, the Director of the U.S. National Institutes of Health and the Cajal Institute. He shared the Eliasson Global Leadership Prize from the Tällberg Foundation in 2018 for his advocacy work.

For information about his research see https://blogs.cuit.columbia.edu/rmy5/ and for his advocacy work see: https://neurorightsfoundation.org/

Talk Title: Neural Data: The Ultimate Privacy Challenge?

Abstract: Neurotechnology is several years behind genomics but is already generating big data that willpose dramatic changes and ethical challenges for society. There are currently no regulatory practices associated with neural data (NeuroData) and its derived societal repercussions. In a seriesof discussions, we explored the strong parallels between the societal challenges associated with the proliferation of Genomic Data and NeuroData. We explored genomics policies in the United States (U.S.), European Union (EU), and United Nations (UN), as a potential model forthe inception of a new NeuroData regulation framework. The ideas generated have inspired current policy efforts on regulation of neural data in Chile and Spain, and they are under initial discussion at the UN. Besides a series of publications, the project also led to one IBM award to explore ethical issues of neurotechnologies, which funded two international meetings on the topic. Finally, we collaborated with the German film director Werner Herzog to make a documentary that discusses neurotechnology and mental privacy.

Larry Au, PhD

Larry Au is an Assistant Professor of Sociology at The City College of New York's Colin Powell School for Civic and Global Leadership. His research examines the dynamics of inclusion and exclusion in the production of biomedical knowledge. Part of this work examines the globalization of precision medicine as a policy idea and scientific project, focusing primarily on its rise in China.

Another part of this research looks at the politics of expertise around Long Covid, in particular, the experience of patients as they navigate uncertainties around their condition in the U.S., Brazil, and China. His research has been published in venues such as Science, Technology, & Human Values, Public Understanding of Science, and Social Science & Medicine. He received his PhD. in Sociology from Columbia University in May 2022.

Talk Title: Precision Medicine in China

Abstract: Although precision medicine the use of genomics and other forms of big data to improve diagnosis and treatment has its origins in the United States, precision medicine took on a new life in China after its introduction in 2011. Chinese scientists seized on ties with mentors and collaborators overseas to rapidly develop this emergent field within China, such that precision medicine was included in key national plans such as the 13th Five Year Plan by 2016. In this presentation, I describe how meanings attributed to precision medicine differ depending on the positions of scientists within national and global scientific networks. For some, precision medicine represented an opening to deepen ties to global science, while for others, precision medicine symbolized an opportunity to use the tools of big data and genomics to modernize traditional Chinese medicine.