



NATIONAL INSTITUTES OF HEALTH

Using Public Engagement to Inform the Use of Data in Biomedical Research
Workshop at University of California, San Diego
February 27, 2023 (All Times PST)



Panelist, Attendee, and Staff Biographies

Panel 1 Panelists



Kolbi Brown

Pyxis Partners

Website: <https://www.pyxispartners.co/>

Title: Director of Stakeholder Engagement

Biography: As a Director at Pyxis Partners, JeKolbi “Kolbi” Brown works to further the firm’s goals of community outreach and engagement for the National Institutes of Health’s (NIH) All of Us Research Program (AoURP) with various stakeholders across the country, as well as other health initiatives for the company.

Prior to his work at Pyxis Partners, Kolbi was the Program Director and Retention Lead for AoURP at NYC Health + Hospitals/Harlem (Harlem Hospital) working within the New York City Consortium, which includes Columbia University Irving Medical Center, Weill Cornell Medicine, and New-York Presbyterian as partners. In this capacity, Kolbi oversaw outreach, engagement, and recruitment efforts with his team enrolling over 2,000 participants into the national cohort.

He also served as Retention Lead for all the NYC Consortium partners, developing and implementing strategies to retain the 26,000 participants enrolled throughout all the consortium sites, with particular focus on overcoming barriers of retaining participants historically underrepresented in biomedical research. Retention as defined by the NIH increased by 15% during the Covid-19 pandemic.

He also served on the Greater Harlem Chamber of Commerce’s Health Committee during the height of the pandemic working to develop programming and initiatives aimed at addressing vaccine hesitancy and increasing vaccination in communities of color.

Kolbi’s work has solidified his belief in the need for an equitable healthcare system, advocacy for communities neglected by current systems and policies, and the importance of engaging communities respectfully and early to effect change. Prior to his involvement with AoURP and joining Pyxis Partners, Kolbi spent ten years managing real estate portfolios for owners across the city. During these years he served as the liaison between ownership and tenant associations.

Kolbi originally hails from Philadelphia, Pennsylvania and received his BA in Political Science from Kutztown University of Pennsylvania. He now resides in the Pocono Mountains with his partner Wesley. In his spare time, he enjoys reading political and historical biographies, tennis, creative writing and painting, and hosting dinner parties for friends and family.



Aaron Coleman

Fitabase

Website: <https://www.fitabase.com/>

Title: CEO and Founder

Biography: Aaron is Founder & CEO of Fitabase, a company dedicated to bringing new and advanced wearable technology tools to the research community. He has spent the last eleven years leading Fitabase from an early experiment to a profitable and sustainable business having been used in over 1,500 research projects to date. Fitabase today continues to develop new initiatives and tools focused on using data and sensors to create innovative ways to improve scientific research. Aaron has studied how to build simple and elegant ready-to-use software solutions that scale and his role is both a business owner and software architect. Prior to Fitabase, Aaron led a small software team at UCSD’s Center for Wireless Population Health Systems that

developed mobile and social-media integrated tools for an intervention promoting healthy lifestyle behavior change. He's also a multiple-time winner of various app hackathons, including Michelle Obama's Apps for Healthy Kids contest, for which he was recognized at the White House.



Rupa Valdez
University of Virginia

Website: <https://engineering.virginia.edu/faculty/rupa-s-valdez>

Title: Associate Professor of Engineering Systems and Environment; Associate Professor of Public Health Sciences

Biography: Dr. Valdez's research focuses on understanding and designing solutions to support the ways in which people manage health at home and in the community. She draws on methods from multiple disciplines including human factors engineering, cultural anthropology, and health informatics, among others. This work encompasses participatory and co-design approaches and attends to the ways in which social networks, physical environment, community resources, and information technology shape patient experiences.

Dr. Valdez is particularly interested in how health is managed among marginalized populations, including racial/ethnic minorities, people with disabilities, and people living in under-resourced settings. A complementary research interest is in methodological development for research and teaching in this space.

She has testified before Congress on the topic of bridging health equity gaps for people with disabilities and chronic conditions. Her editorial appointments include serving as Associate Editor for Ergonomics, the Journal of American Medical Informatics Association Open, and Human Factors in Healthcare. Among other appointments, she serves on the Board of Directors for the American Association of People with Disabilities and for the American Health Information Management Association Foundation. She also serves on PCORI's Patient Engagement Advisory Panel and the National Committee for Quality Assurance's Health Equity Expert Work Group. She is also the Founder and President of the Blue Trunk Foundation.



Jennifer Wagner
Pennsylvania State University

Website: <https://pennstatelaw.psu.edu/faculty/wagner>

Title: Assistant Professor of Law, Policy, and Engineering

Biography: Dr. Wagner is Assistant Professor of Law, Policy, and Engineering and holds additional faculty affiliations with Penn State Law, Department of Biomedical Engineering, Institute for Computational and Data Sciences, and Rock Ethics Institute. She has been a licensed attorney practicing in Pennsylvania part-time since 2007.

Dr. Wagner is a multidisciplinary expert whose research has been focused on the international human right to science, including human-centered design and matters of nondiscrimination, privacy, and equity with genetic/omic and mobile/digital health technologies. She's published over 60 journal articles, her work has been cited by the Supreme Court of the United States, and her research has been funded by awards from the National Human Genome Research Institute, National Institute of Dental and Craniofacial Research, National Institute of Biomedical Imaging and Bioengineering, NIH Office of the Director, and National Cancer Institute.

Prior to joining Penn State, Dr. Wagner conducted ethical, legal, and social implications (ELSI) research at Duke University's Institute for Genome Sciences and Policy, the University of Pennsylvania's Center for the Integration of Genetic Healthcare Technologies, and Geisinger's Center for Translational Bioethics & Health Care Policy. As a AAAS Science & Engineering Congressional Fellow, she assisted with judiciary, science, and privacy policy issues in a US Senator's office.

Dr. Wagner is an active member of several professional organizations and has held several leadership positions, including as chair of the ASHG Social Issues Committee, co-chair of the Ethics Committee for the American Association of Biological Anthropologists, member of the Pennsylvania Bar Association's Cybersecurity & Data Privacy Committee, member

of the American Association for the Advancement of Science (AAAS) Committee on Scientific Freedom and Responsibility, and Associate Editor for Human Genetics and Genomics Advances.

Panel 2 Panelists



Mildred Cho

Stanford University

Website: <https://profiles.stanford.edu/mildred-cho>

Title: Assistant Professor of Law, Policy, and Engineering

Biography: Mildred Cho is a Professor in the Department of Pediatrics Division of Medical Genetics and in the Department of Medicine at Stanford University. Dr. Cho's major areas of interest are the ethical and social impacts of genetic research and data science and their applications, including AI and machine learning for precision medicine, gene therapy, the human microbiome, and synthetic biology.



Lisa Lehmann

Harvard University

Website: <https://www.linkedin.com/in/lisa-lehmann-aa980245>

Title: Director of Bioethics

Biography: Lisa Soleymani Lehmann is a primary care physician and bioethicist. She is Associate Professor of Medicine at Harvard Medical School (HMS) and Associate Professor of Health Policy and Management at the Harvard T. H. Chan School of Public Health.

From 2020-2023 Lisa was Director of Bioethics at Google where she established the Bioethics Program to address ethical issues in AI, technology, and society. She chaired the Google Health Ethics Committee and worked with engineers and researchers to embed ethics into products, policy, and organizational decisions.

Lisa previously held positions as Chief Medical Officer (2017-2020) for the VA New England Healthcare System which is a multi-state integrated healthcare system comprised of 8 medical centers and 41 community-based outpatient clinics that serves over 260,000 Veterans. Prior to serving VA New England, Lisa was Executive Director of the VA National Center for Ethics in Health Care, Director of Bioethics at Brigham and Women's Hospital, and a practicing primary care physician and health services researcher at Brigham and Women's Hospital.

Lisa holds a BA from Cornell University where she was a College Scholar and has an MD and PhD in Philosophy from Johns Hopkins University. She has a Master of Science in Clinical Epidemiology from the Harvard T. H. Chan School of Public Health. She was an Osler intern and resident at Johns Hopkins Hospital and was a fellow in the Harvard Fellowship in General Internal Medicine and Primary Care.



Monica Rodriguez

Pyxis Partners

Website: <https://www.pyxispartners.co/>

Title: Senior Director, Pyxis Partners

Biography: As Senior Director at Pyxis Partners, Monica helps drive forward the firm's engagement efforts for various clients by providing them with the opportunity to make sustainable decisions through open dialogue and collaborative work with community members.

Prior to her work with Pyxis Partners, Monica was the Director of Communications and Engagement at Northwestern University where she was responsible for facilitating communication, strategy development and implementation of the All of Us Research Program within the hospital network and the community.

Passionate about widening access to health care for underserved populations, Monica is skilled at cross cultural communication and building partnerships with diverse community organizations. She holds a BA in Communications from Bradley University and an MA from Roosevelt University.

Monica Rodriguez is a first-generation Colombian American who resides in Chicago with her partner. She volunteers with the Chicago Architecture Foundation as a docent, is a YP Ambassador with the Chicago Council on Global Affairs and in her free time can be found long distance biking, traveling, or playing D&D.



Jay Schnitzer

MITRE

Website: <https://www.mitre.org/who-we-are/our-people/jay-schnitzer>

Title: Senior Vice President, Chief Technology Officer, Chief Medical Officer

Biography: Dr. Schnitzer directs MITRE's independent research and development (R&D) program and manages development of corporate technology strategy, which spans MITRE's operating centers and sponsor community. He also leads corporate and national initiatives in health and life sciences, building coalitions leveraging the best talent across the nation in these communities. Previously, as the director of biomedical sciences at MITRE, Schnitzer oversaw the organization's health transformation R&D program.

Before joining MITRE, Schnitzer was the director of the Defense Sciences Office at DARPA, where he led a team of 20 program managers and 70 support staff overseeing R&D across multiple domains. In addition to life sciences, biomedical research, and quantum physics, these R&D areas included materials science, advanced mathematics, and engineering.

Formerly, Schnitzer was chief medical officer and senior vice president at Boston Scientific Corporation (BSC). His responsibilities at BSC included medical and clinical oversight of the entire product lifecycle for all medical devices manufactured by four business divisions of the company: endoscopy, urology/women's health, neurovascular, and neuromodulation.

Prior to BSC, Schnitzer was on staff at Massachusetts General Hospital as an attending pediatric surgeon, with a joint appointment at the Shriners Hospital for Children burn center and a faculty position at Harvard Medical School. In recognition of his work on the COVID-19 Healthcare Coalition and his leadership of the MITRE independent R&D program, *Washington Exec* named Schnitzer its 2020 Healthcare Industry Executive of the Year. The award recognizes executives fostering innovation for the federal government.

Panel 3 Panelists



Shaun Grannis

Indiana University School of Medicine, Regenstrief Institute

Website: <https://www.regenstrief.org/person/shaun-grannis/>

Title: Vice President, Data and Analytics; Research Scientist, Center for Biomedical Informatics; Regenstrief Chair in Medical Informatics, Indiana University School of Medicine; Professor of Family Medicine, Indiana University School of Medicine

Biography: Dr. Shaun Grannis collaborates closely with national and international public and population health stakeholders to advance the technical infrastructure and data-sharing capabilities in varying settings. His research is focused on improving discovery and decision support in a variety of contexts by developing, testing, and implementing innovative approaches for data integration, patient matching, predictive modeling and other novel data science use cases, including developing novel population health data frameworks supporting fusion of community and social determinants of health with clinical data, as

well as leveraging machine learning-based models to improve discovery and decision support in a variety of contexts. He currently leads the Linkage Honest Broker team as part of the NCATS N3C initiative.

Dr. Grannis has been a part of Regenstrief Institute since 2001 when he began a National Library of Medicine sponsored medical informatics fellowship. He became the Associate Director of the Clem McDonald Center for Biomedical Informatics at Regenstrief in 2015 and was appointed Director in 2017. He assumed the role of Vice President in 2019.



Lucila Ohno-Machado

Yale School of Medicine

Website: <https://medicine.yale.edu/news-article/lucila-ohno-machado-md-phd-mba-will-lead-biomedical-informatics-and-data-science/>

Title: Deputy Dean for Biomedical Informatics

Biography: Dr. Ohno-Machado was recently appointed deputy dean for biomedical informatics and will lead the newly created free-standing Section for Biomedical Informatics and Data Science at the Yale School of Medicine. As deputy dean for biomedical informatics, Ohno-Machado will oversee the infrastructure related to biomedical informatics research across the academic health system.

Dr. Ohno-Machado was previously health sciences associate dean for informatics and technology, founding chief of the Division of Biomedical Informatics in the Department of Medicine, and distinguished professor of medicine at the University of California San Diego (UCSD). She also was founding chair of the UCSD Health Department of Biomedical Informatics and founding faculty of the UCSD Halicioğlu Data Science Institute in La Jolla, California.

She organized the first large-scale initiative to share clinical data across five UC medical systems and later extended it to various institutions in California and around the country. Prior to joining UCSD, she was distinguished chair in biomedical informatics at Brigham and Women's Hospital, and faculty at Harvard Medical School and at MIT's Health Sciences and Technology Division. She is an elected member of the National Academy of Medicine, the American Society for Clinical Investigation, the American Institute for Medical and Biological Engineering, the American College of Medical Informatics, and the International Academy of Health Sciences Informatics. She is a recipient of the American Medical Informatics Association leadership award, as well as the William W. Stead Award for Thought Leadership in Informatics.



Ronnie Tepp

Pyxis Partners

Website: <https://www.pyxispartners.co/>

Title: Principal

Biography: Ronnie Tepp has spent the past three decades working to craft and advance policy and programs to improve outcomes for patients. At Pyxis Partners, she serves as the Principal Investigator (PI) for the engagement awardee team to the National Institutes of Health's All of Us Research Program. In this role, she leads and manages a team tasked with reaching, educating and engaging underrepresented communities in medical research to build an All of Us participant community truly reflective of our country. Ronnie and the Pyxis team have built out a national network of trusted messengers and have developed an infrastructure to educate and support them in bringing the program to their communities.

In addition to this work, Ronnie specializes in strategy and policy development, coalition-building, strategic planning and advocacy. She has a talent for bringing stakeholders and nontraditional groups together to develop and advance collective agendas. She has an impressive track record and has proactively identified opportunities to promote good policy, helped organizations and communities coalesce around a common strategy and built trust internally to maximize their impact. The result has been the development of formidable coalitions that have succeeded in uniting and amplifying the voice of their communities and affecting change for the benefit of patients and families.

Ronnie's career has included service as a senior-level congressional staffer during the health reform debates of the 1990s, vice president of a lobbying firm representing academic medical centers and health advocacy organizations, and chief lobbyist for the Juvenile Diabetes Research Foundation (JDRF).

A native of Massachusetts and a graduate of Skidmore College and Georgetown University, Ronnie lives with her husband and three children in Vienna, Virginia. She serves as a Board member of the Crohn's and Colitis Foundation DC/Northern Virginia Chapter and as a mentor with New Hope Housing in Alexandria, VA, providing support to clients in their residential homes and shelters.



Krystal Tsosie

Arizona State University

Website: <https://search.asu.edu/profile/535281>

Title: Assistant Professor, School of Life Sciences

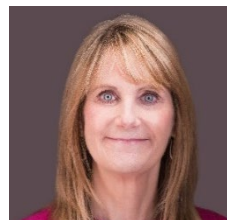
Biography: Dr. Tsosie (Diné/Navajo Nation) is an Indigenous geneticist-bioethicist. As an advocate for Indigenous genomic data sovereignty, she co-founded the first US Indigenous-led biobank, a 501c3 nonprofit research institution called the Native BioData Consortium.

Her research can be encapsulated in two main foci: Indigenous population genetics and bioethics. In particular, she focuses on bioethical engagement of Indigenous communities in genomics and data science to build trust. As a whole, her interest is in integrating genomic and data approaches to assess Indigenous variation contributing to health inequities.

She began her research career at the laboratory bench, where she developed and patented a combined targeted ultrasound imaging and chemotherapeutic drug delivery device for treating early metastases in cancer. Upon seeing the disparities in emerging genomics technologies, she switched fields to genetic epidemiology, public health, and bioethics. Her first Master of Arts in Bioethics at Arizona State University focused on the cultural implications of genetics in Native American communities. She added biostatistical knowledge and computational programming in large genomics datasets during her second Master's in Public Health (genetic epidemiology) at Vanderbilt University, where she studied disparities in uterine fibroids in African American women. She has co-led an ongoing longitudinal genetics study in a North Dakota Tribal community. This project serves as one of few examples of community-based participatory research involving genetics in an Indigenous tribal nation.

Her research and educational endeavors have received increasing national and international media attention as scientists worldwide are understanding the importance of equitable, community-based engagement models and the importance of Indigenous genomic data sovereignty. Her work has been covered by popular media outlets including PBS NOVA, The Washington Post, NPR, New York Times, The Atlantic, Forbes, and Boston Globe. She currently serves on the Government Policy and Advocacy Committee for the American Society of Human Genetics and the National Academy of Medicine Announces Committee on Emerging Science, Technology, and Innovation. She is a current Global Chair in ENRICH (Equity for Indigenous Research and Innovation Coordinating Hub), which focuses on enhancing Indigenous rights to develop, control, and govern Indigenous data and supports participation in STEM and in digitally-enabled futures.

Panel 4 Panelists



Deven McGraw

Invitae

Website: <https://www.linkedin.com/in/deven-mcgraw-6650285>

Title: Lead, Data Stewardship & Data Sharing

Biography: Deven McGraw is the lead for Data Stewardship and Data Sharing at Invitae, a clinical genetic medicine company. Previously, she co-founded and served as Chief Regulatory Officer for Ciitizen, a platform for patients to gather and manage their health information, prior to its acquisition by Invitae in 2021. From 2015-2017, she directed U.S. health privacy and security as Deputy Director, Health Information Privacy at the HHS Office for Civil Rights and Chief Privacy Officer (Acting) of the Office of the National Coordinator for Health IT. She was recently appointed by GAO to a three-year term on the Health Information Technology Advisory Committee. Widely recognized for her expertise in health privacy, she directed the Health Privacy Project at the Center for Democracy & Technology for six years, testifying before Congress on health privacy issues on multiple occasions and leading the privacy and security policy work for the HITECH Health IT Policy Committee.

She also is currently serving on the Data and Surveillance Workgroup of the CDC's Advisory Committee to the Director on CDC's Data Modernization. She previously was the Chief Operating Officer of the National Partnership for Women and Families and, before joining federal government service, advised health industry clients on HIPAA compliance and data governance while a partner at Manatt, Phelps & Phillips, LLP. Deven graduated magna cum laude from Georgetown University Law Center and has a Master of Public Health from Johns Hopkins University.



Maya Sabatello
Columbia University

Website: <https://www.columbiapsychiatry.org/profile/maya-sabatello-llb>

Title: Associate Professor of Clinical Bioethics

Biography: Dr. Sabatello specializes in bioethics, medical ethics, disability studies, international law and comparative human rights. A lawyer with a PhD in political science, and post-doctoral training from Harvard Medical School and Columbia University Medical Center, her work is interdisciplinary and cross-cultural. Her research focuses on law, society, and disability; a child-centered approach to assisted reproductive technologies; and the ethical, legal, and social implications of genetics, especially in pediatrics and judicial settings. She is the author of *Children's Bioethics* (Martinus Nijhoff/ Brill Publishing, 2009) and co-editor of *Human Rights and Disability Advocacy* (Penn University Press, 2014).

Previously, Dr. Sabatello litigated cases of medical malpractice and has worked as a legal adviser to national and international nongovernmental organizations to promote health-related human rights. As a Permanent Representative for a nongovernmental organization at the United Nations, she participated in the drafting of the Convention on the Rights of Persons with Disabilities. Dr. Sabatello chairs the AAAS's Ethics and Human Rights Working Group, co-chairs the ASIL's International Disability Rights Interest Group, and serves as a member at various genomic-related committees at Columbia University.

NE_xTRAC Working Group Attendees, Moderators



Lorraine Albritton

University of Tennessee Health Science Center

NE_xTRAC Committee Member

Member of NE_xTRAC Working Group on Data Science and Emerging Technology

Website: <https://www.uthsc.edu/medicine/molecular-sciences/faculty-directory/albritton.php>

Title: Professor Emeritus, Department of Microbiology, Immunology, and Biochemistry

Biography: Dr. Albritton served on the Recombinant DNA Advisory Committee (RAC) to the Director of NIH from 2016-2018 and was appointed by the Director to serve on the Novel and Exceptional Technologies Advisory Committee (NE_xTRAC) when it was organized from the former RAC in 2018. Dr. Albritton served on the Working Group to Establish a NE_xTRAC Framework to assess potential issues that may occur as new biotechnologies are developed and applied; the Gene Drives in Biomedical Research Working Group to develop a path forward for biomedical research involving gene drive-modified organisms for biomedical research; and is currently a member of the Working Group on Data Science and Emerging Technology.



Cinnamon Bloss

University of California, San Diego

Current Chair of NE_xTRAC Committee

Member of NE_xTRAC Working Group on Data Science and Emerging Technology

Website: <https://profiles.ucsd.edu/cinnamon.bloss>

Title: Professor of Public Health, Psychiatry, and Medicine

Biography: Dr. Cinnamon Bloss is a tenured Professor of Public Health, Psychiatry, and Medicine at the University of California San Diego. She is the Founding Director of the Center for Empathy and Technology, situated within the UCSD Institute for Empathy and Compassion, where she also serves as Associate Director. Dr. Bloss conducts interdisciplinary research focused on social and behavioral phenomena related to emerging information and biotechnologies. Her research has been funded by the National Institutes of Health, the Defense Advanced Research Projects Agency, and philanthropic donations. In 2021, Dr. Bloss was appointed by the NIH Director to serve as Chair of the Novel and Exceptional Technology and Research Advisory Committee, a federal advisory committee that provides recommendations to the NIH Director and a public forum for the discussion of scientific, safety, and ethical issues associated with emerging biotechnologies. Prior to assuming the chairpersonship of the committee, she served as Co-chair of the Gene Drives in Biomedical Research Working Group. Dr. Bloss was recognized by the Western Societies of Medicine with the Carmel Prize for Research Excellence and has published over 100 papers. She was honored by the American Society of Human Genetics as the recipient of the 2022 Mentorship Award and has mentored over 50 trainees. She has received multiple teaching awards at UCSD, where she also founded a new concentration in Technology and Precision Health for the Master in Public Health degree. Dr. Bloss currently serves as Interim Assistant Dean of Academic Affairs in the Herbert Wertheim School of Public Health. She is a California-licensed clinical psychologist.



Sachin Kheterpal

University of Michigan Medical School

Co-Chair, NE_xTRAC Working Group on Data Science and Emerging Technology

Website: <https://medicine.umich.edu/medschool/leadership/sachin-kheterpal-md-mba>

Title: Associate Dean for Research Information Technology; Professor of Anesthesiology

Biography: Dr. Kheterpal is responsible for establishing the vision and strategy to effectively use information technology (IT) to advance the University of Michigan Medical School's research mission. Working closely with Health Information Technology and Services, the Michigan Institute for Clinical & Health Research (MICH_R), departmental leadership, and other

research and informatics teams across the Medical School, he sets research IT priorities to help ensure our competitive positioning for the future. To that end, he will coordinate centralized research IT efforts with departmental points of distributed innovation and champion the use of IT to differentiate Michigan Medicine in securing extramural funding, establishing industry partnerships, and attracting and retaining top faculty, staff and students. Additionally, he serves as a liaison to U-M campus research IT leadership to maximize the research impact of an integrated computing environment.

Kheterpal received his Bachelor of Science, Doctorate of Medicine, and Master in Business Administration degrees from the University of Michigan. His career has been focused on the novel use of IT and electronic health records (EHR) for patient care, quality improvement and research. He is recognized as a national leader in perioperative large dataset clinical research and has published numerous articles, editorials and book chapters regarding intraoperative management and long-term postoperative outcomes. Using innovative techniques to integrate administrative, EHR, and registry data across institutions, he leads the Multicenter Perioperative Outcomes Group. The group has accumulated more than six million patient records with risk-adjusted outcomes and detailed clinical intervention data spanning more than 30 health systems across the U.S. and Europe for outcomes research and quality improvement.

He also serves as director for the Anesthesiology Performance Improvement and Reporting Exchange (ASPIRE) Collaborative Quality Initiative, is a member of the advisory panel for the National Institutes of Health (NIH) Precision Medicine Initiative Cohort Program, and recently appointed to the NIH's Council of Councils.



Debra Mathews

Johns Hopkins University

Member of NExTRAC Working Group on Data Science and Emerging Technology

Website: <https://iaa.jhu.edu/people/debra-mathews/>

Title: Assistant Director for Science Programs, Johns Hopkins Berman Institute of Bioethics; Associate Professor, Department of Genetic Medicine

Biography: Dr. Mathews is the Ethics & Governance Lead at the Institute for Assured Autonomy and serves as a liaison with the Berman Institute of Bioethics. Dr. Mathews leads work focused on the ethical, societal, and governance implications of autonomous systems, and identifies opportunities across IAA activities for the integration of ethics and governance work and priorities.

Her academic work focuses on ethics and policy issues raised by emerging technologies, with particular focus on genetics, stem cell science, neuroscience, synthetic biology, and artificial intelligence. In addition to her academic work, Dr. Mathews has spent time at the Genetics and Public Policy Center, the US Department of Health and Human Services, the Presidential Commission for the Study of Bioethical Issues, and the National Academy of Medicine working in various capacities on science policy.



Pilar Ossorio

University of Wisconsin-Madison

NExTRAC Committee Member

Co-Chair, NExTRAC WG on Data Science and Emerging Technology

Website: <https://secure.law.wisc.edu/profiles/pnossorio@wisc.edu>

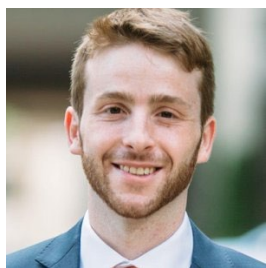
Title: Professor of Law and Bioethics

Biography: Dr. Ossorio is on the faculties of the Law School and the Department of Medical History and Bioethics at the Medical School. In 2011 she became the inaugural Ethics Scholar-in-Residence at the Morgridge Institute for Research, the private, nonprofit research institute that is part of the Wisconsin Institutes of Discovery. She also serves as the co-director of UW's Law and Neuroscience Program, as a faculty member in the UW Masters in Biotechnology Studies program, and as Program Faculty in the Graduate Program in Population Health. Prior to taking her position at UW, she was Director of the Genetics Section of the Institute for Ethics at the American Medical Association, and taught as adjunct faculty at the University of Chicago Law School.

Throughout her career Dr. Ossorio has participated in numerous advisory committees and boards that aid governments in setting science policy. She has advised the U.S. National Institutes of Health and the FDA, Genome Canada, and Health Canada. In 2012 she was appointed to a four year term on the Secretary's Advisory Committee on Health Research Protections, a committee to advise the Secretary of Health and Human Services on how to improve protections for people who participate in biomedical and behavioral research. She recently completed a term on the National Advisory Council for Human Genome Research, and she has served on or chaired numerous committees and working groups that advise large-scale genome research initiatives, such as the 1000 Genomes Project and the Human Microbiome project. She has also served as a member of, or liaison to, several Boards and Committees for the Institute of Medicine and the National Research Council (both part of the National Academies of Science), including the National Cancer Policy Board, the Human Embryonic Stem Cell Advisory Committee, and the Committee on Intellectual Property Rights. She is an elected fellow of the American Association for the Advancement of Science (AAAS).

Dr. Ossorio's research interests revolve around research ethics and the protection of research participants, including: governance of large bioscience projects; data sharing in scientific research; the use of race in biomedical and social science research; ethical and regulatory issues in human subjects research; and the regulation and ethics of online research. She is also quite interested in novel ethical, regulatory, and policy issues raised by research aimed at moving scientific and engineering findings from the laboratory to the product development and medical/therapeutic applications (translational research).

NIH Office of Science Policy



Jesse Isaacman-Beck

Health Science Policy Analyst

Biography: Jesse Isaacman-Beck is a Health Science Policy Analyst in the Office of Science Policy, working as special assistant to the Acting Director of the Office. In addition to staffing the NExTRAC Working Group, he assists with the development of NIH Public Access Policies, has staffed the NIH UNITE Initiative to end structural racism in Biomedical research, and has been a delegate to the OECD Working Party on Biotechnology, Nanotechnology and Converging Technologies. Before joining the NIH, Jesse was a postdoc in the department of Neurobiology at Stanford University and received his Ph.D. in Neuroscience from the University of Pennsylvania, where he conducted research on molecular mechanism of visual processing and nerve regeneration. Throughout his scientific training, Jesse founded and led programs and developed policies to increase opportunity and equity in biomedical research.



T.J. Kasperbauer

AAAS Science and Technology Policy Fellow

Biography: T.J. Kasperbauer is an AAAS Science and Technology Policy Fellow in the Office of Science Policy, working in the Scientific Data Sharing Policy Division. In addition to staffing the NExTRAC Working Group, he assists with the oversight of the NIH Genomic Data Sharing Policy and the NIH Data Management and Sharing Policy. Before joining the NIH, T.J. was a postdoc at the Indiana University School of Medicine and Center for Bioethics, where he conducted research on patient and research participant attitudes toward data sharing and informed consent.



Jessica Tucker

Acting Deputy Director

Biography: Dr. Tucker is the Acting Deputy Director of the Office of Science Policy at NIH. In this position, she helps provide leadership on a number of policy topics that impact biomedical research. She previously served as the Director of the Division of Biosafety, Biosecurity, and Emerging Biotechnology Policy within the Office of Science Policy, where she led work on a number of policy topics, including the NIH Guidelines for Research Involving Recombinant or Synthetic Nucleic Acid Molecules, dual use research, and emerging biotechnologies.

Previously, Dr. Tucker was a Program Director at the National Institute for Biomedical Imaging and Bioengineering (NIBIB) at NIH where she managed a program on gene and drug delivery systems and on synthetic biology. Prior to her time at NIH, she worked at HHS in the Office of the Assistant Secretary for Preparedness and Response, which she joined initially as an American Association for the Advancement of Science Policy Fellow. Prior to her time at HHS, Dr. Tucker was a Visiting Assistant Professor at Stony Brook University within the Department of Technology and Society, where she conducted engineering education research and lectured within the Department of Chemical and Molecular Engineering. Dr. Tucker worked for two years in research and development in the pharmaceutical industry.

Palladian Partners

Website: <https://www.palladianpartners.com/>

Palladian Partners is a full-service marketing and communications firm that has provided conference service support to the NIH Office of Science Policy for over ten years. Palladian works with respected government agencies, organizations, and businesses to unlock the potential of their health and science communications.



Leslie McClain

Senior Conference Planner/Project Manager



Amanda Hennessey

Conference Planner



Jessica Clark

Project Director