## **Designing Impactful Informed Consent Processes that Empower Participants**





## **Health Literacy Month Webinar Series**

Designing Impactful
Informed Consent Processes
that Empower Participants

October 10, 2024 12 - 1 PM ET

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## Webinar Speaker Biographies



Moderator: Sylvia Baedorf Kassis, MPH, is a Program Director at the MRCT Center. Sylvia joined the MRCT Center in January 2018 and previously held the Program Manager position at the Center. Sylvia brought with her more than 20 years of clinical research-related experience in Canada and the United States of America. Her expertise includes ethical/regulatory review of research, clinical trial workforce training and capacity building, and study coordination, management, and oversight. Sylvia champions making clinical research more understandable and accessible to patients, participants, and caregivers through her work on Health Literacy in Clinical Research and the first-of-its-kind, plain-language Clinical Research Glossary. In addition,

she supports other MRCT Center initiatives in applying health literacy principles to their outputs. Sylvia is passionate about patient/participant engagement and, as such, strives for inclusivity in the programs she leads so that patient/participant voices are prioritized.

Sylvia's clinical research interests include understanding study participants' experiences in research and incorporating their insights into study processes, supporting research coordinators through networks and training, and ensuring all research stakeholders have the resources they need to conduct ethical and compliant studies involving study participants and their data/samples. Sylvia earned a Master of Public Health degree in Global Health from Boston University School of Public Health (2008) and a Bachelor of Science from the University of Toronto (2001)



Marianna Azar, MA is a Program Specialist with the Division of Education and Development at the Office for Human Research Protections (OHRP), U.S. Department of Health and Human Services. Before joining OHRP, Ms. Azar served as Director and Chair of the Institutional Review Boards for the New York City Department of Education. Prior to that, she was employed as a Human Research Protection Program Manager at the City University of New York Graduate Center, and as an IRB Specialist at Columbia University's Human Research Protection Office. Marianna holds a BA in Philosophy from the State University of New York at Oswego, an MA in Philosophy and a Graduate Diploma in Health Services and Policy Research from York University in Toronto, Canada, and is also

working on completing her Ph.D. in Bioethics at York University.



Katherine Blizinsky, PhD, (she/they) is honored to lead a group of extremely talented policy practitioners and ethical, legal, and social implications (ELSI) scholars as the director of policy for the All of Us Research Program. They completed their doctoral and postdoctoral training at Northwestern University before receiving the American Society of Human Genetics/National Human Genome Research Institute (NHGRI) Genetics and Public Policy Fellowship. Dr. Blizinsky began their policy career on Capitol Hill, working with the Senate Health, Education, Labor, and Pensions Committee, negotiating and drafting the 21st Century Cures Act. Subsequently, they moved to National Institutes of Health (NIH), where they held simultaneous appointments as policy

advisor to the fledgling All of Us Research Program and as an intramural research fellow with the NHGRI's Health Disparities Unit. Their work at All of Us has drawn on their expertise in the areas of participant protections, informed consent, data

governance models, and the ethical conduct of research, and in 2023, they received a Special Act Award from NIH for their contributions to ethical models for data science. A neuroscientist and geneticist, specializing in research on gene-environment interaction, with a focus on health equity, Dr. Blizinsky continues to be involved in academic research, through the NIH intramural program, and education, lecturing at Georgetown University and the University of Washington.