

BIOETHICS BULLETIN

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INTERVIEW WITH LEILA JAMAL, SCM, PHD, CGC

Leila Jamal, adjunct faculty in the NIH Department of Bioethics, reflects on her experience with the Department.



Q. How did you first become interested in bioethics, and were there any specific issues that initially sparked your interest?

My experience of growing up in several different countries made it clear to me that while human beings share fundamental attributes and needs, we organize ourselves into different kinds of societies based on different norms and value systems. To adapt to new environments and form relationships in new places, I had to integrate these different norms and value systems into a coherent yet flexible

worldview. That's where it all began. I started to formally cement my interest in ethics and epistemology when I took a Theory of Knowledge class as part of the International Baccalaureate in high school. This led me to study Philosophy, Politics, and Economics at Oxford as an undergraduate. While I've never considered myself a philosopher, I have always found ways to integrate applied ethics into whatever I am doing. I love the conceptual rigor of it and the fact that you can apply ethical reasoning to just about anything in life. When I became a genetic counselor, I realized that my work was full of conceptual ambiguity and ethical complexity. Paradoxically, genetic counseling is a field that has typically eschewed rigorous normative scholarship in favor of "non-directiveness". I saw a scholarly gap there and became interested in filling it, and since then I haven't looked back!

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We had a full house for our class of '24 graduation gathering.



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CHRISTINE'S CORNER

*Greetings from the NIH CC
Department of Bioethics!*



Sending my warmest greetings and best wishes to all of you, and hope that you and yours are healthy and flourishing as we move into the fall 2024.

With all of your contributions, our Department of Bioethics is and remains strong; committed to a robust community, excellence in our work, and making a difference in the lives of others. We are very fortunate for the many smart, productive, and curious people who have and continue to make the department a wonderful place to work.

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JASMINE GUNKEL, PHD: INTIMACY AND BIOETHICS

Jasmine Gunkel is a second-year postdoctoral fellow in the department. She holds a PhD in Philosophy from the University of Southern California. Starting Fall 2025, she will be assistant professor of Philosophy at Western University in Ontario, Canada.

My research centers around intimacy. In [prior work](#), I've developed a philosophical account of what intimacy is and why it matters, an account that I believe can explain the particular stringency of our intimate rights. Understanding intimacy helps us see why some procedures, like gynecological exams or psychological evaluations, are more likely than other procedures, like teeth cleaning or blood draws, to feel deeply personal and make patients psychologically vulnerable. I argue that commonly leaned on concepts, like privacy or bodily autonomy, are inadequate for capturing these distinctions.

While at the NIH, I am working on a number of projects that focus on the intimacy of medical care and its moral upshots. I've argued that we have [overlooked intimate violations](#) when thinking about the potential harms of research. Harisan Nasir and I are working out why it is particularly troubling to use our intimate information "against us" for insurance pricing, even though it can make insurance more actuarially fair. In another paper, I explore norms of reciprocity in vulnerable sharing and the reasons doctors ought to sometimes self-disclose to patients.

Finally, I am thinking about the possibility of genuine intimacy with AI systems (or if only 'pseudointimacy' is possible) and what turns on this. The surgeon general has declared that we're in an "epidemic of loneliness." I aim to shed new light on where AI might ease the burdens of loneliness and where it is an inapt salve. I hope, in addition to saying some lofty things about the value of human connection, to generate some useful proposals about how we ought to regulate these systems, from AI "friends" to therapy chatbots.

CHRISTINE'S CORNER, CONTINUED

As mentioned last year, most of us are working in the office at least 3 or 4 days a week with meetings and seminars and tea in person (usually with a hybrid option), it feels a lot like the pre-2020 days! The Bioethics Consultation service is active and seems greatly appreciated by others at NIH, and we are getting close to naming a replacement for Marion to lead the Consult service. We are also getting ready to welcome a new cohort of exceptional fellows who bring a variety of interests and experiences.

We have some new faces again this year. Alex Welna and Nathan Smith have joined us to help Yukiko with her important research on measurement of inequity and public deliberation. Mira Raju will be joining us as a research assistant any day now, as Connor Sullivan has moved on to a position at Google. Anya Prince is back spending some time with us as she continues her work on ethics and genomics. David DeGrazia will be back to join us as a visiting scholar for the academic year. There is a new NIH Director since last year, Dr. Gilman (CC CEO) is leaving at the end of 2024, and there are many other changes in leadership across the ICs.

Despite the enormous challenges of the past several years, we have learned a lot and I sense renewed hope and energy. We must continue to be bold and take chances and do things that matter. As Wayne Gretzky said (although I know little about hockey 😊): "You miss 100% of the shots you don't take."

I hope that you are continuing to tackle important ethical questions, not throwing away your shot, and trying to make a difference. Please stay healthy, happy, and productive. You are always welcome to visit us, present a work in progress, collaborate with us on a project, or just join us for tea.

Warmest wishes, Christine

INTERVIEW WITH LEILA JAMAL (CONTINUED)

Q. What brought you to the NIH Department of Bioethics? How does your work here align with your roles at Johns Hopkins and the National Cancer Institute?

When I finished my PhD, my life and family circumstances did not make it feasible for me to pursue a postdoc. I came to the NIH because it's a unique environment where clinical care and research overlap, and I knew I would find a way to use my eclectic skillset here. My first NIH job was as a clinical counselor for the National Institute of Allergy and Infectious Diseases, where I helped establish what is now the largest genomic sequencing protocol in the NIH Intramural Program. My supervisors there were generous enough to build some protected research time into my role. In that time, I began to collaborate on projects with Bioethics faculty members and fellows. When I moved into my role at the National Cancer Institute, I took on more teaching and research in lieu of doing clinical care, and my relationship to the department became even more fruitful. I started seeing consults on the ethics consult service this year and it has been extremely rewarding.

Q. What projects are you currently working on? How do you select the topics for your research, and what motivates you to pursue them?

I'm very interested in the idea that while genetics is often exceptionalized because of its significance to whole families, we don't often operationalize and use genetics in ways that maximize its benefits to families. Much of my work focuses on how to deliver genomic services in a post-genetic-exceptionalism era. I'm also interested in how conversations about genetics transpire at the end of life, when the main benefit of genetic risk assessment accrues to a patient's family members. In general, all the topics I pursue originate from clinical dilemmas or tricky cases I have seen in the past.

Q. Of the various topics you've addressed over the course of your career, what have you found most enjoyable, or most challenging to work on?

My favorite topics are the ones brought to my awareness by trainees, because that is how I gain exposure to continuous learning and stay intellectually nimble. My most recent favorites have been some trainee-led projects related to the responsible conduct and dissemination of genetic research with and about LGBTQI+ people.

Q. What do you enjoy most about being in the department?

The NIH Bioethics Department is an extremely trainee-friendly environment that feels sincerely collaborative and eager to help the NIH community in any way it can. The academic culture of the department is rigorous and ambitious, but not in a way that pits scholars against one another. Although I was never formally invited to be a member of this community, I have always felt welcome and supported.



Tea is still going strong! Birthday celebrations are still a regular occurrence. We most recently celebrated Holly and Emily's birthdays.

INTERVIEW WITH ERIKA BLACKSHER, PHD

Erika Blacksher is a research professor in the Department of History and Philosophy of Medicine at the University of Kansas School of Medicine and an affiliate associate professor in Department of Bioethics and Humanities at the University of Washington. She visited the NIH Department of Bioethics for a week during Spring 2024.

Q. What were you doing prior to visiting the department?

I was working on several projects and papers and made a visit to Oxford University. One of the projects I lead is called [HealthCommons](#), a community deliberation toolkit designed to support organizations in the difficult task of engaging diverse people from across the political spectrum to learn and problem-solve together about community health challenges. Communication and political science shows that population health information and science is not only unfamiliar to most Americans but that it can also trigger partisan responses among some. My team and I designed a toolkit with briefing materials, case studies, a facilitator guide, expert presentations, and more that was informed by communication strategies that might help circumvent pitfalls in population health messaging. The design-build phase of the project was funded by County Health Rankings & Roadmaps, and I am now laying the groundwork for a proof-of-concept phase.



My visit to Oxford University was also about public deliberation. Leadership at Oxford's Ethox Centre gathered some dozen deliberation scholars and practitioners from around the world to talk about their work and begin considering questions about the use of public deliberation in the context of global health. The next meeting is in Bangkok in October.

In addition to working on the paper I had been invited to present in the Department of Bioethics, which I say more about below, I had been working on a paper for the National Academy of Medicine that will be part of a new collection of papers on structural racism and health inequities. I had the privilege of writing the paper with two people whose work I greatly respect and have long used, Drs. Matt Wray and Steven Woolf; the collection is anticipated to be released in 2025.

Q. Why were you interested in visiting the department?

The NIH Department of Bioethics is a stronghold of bioethics, and I looked forward to meeting the scholars and fellows in the department. But my more specific reasons were threefold. First, the invitation came from my colleague Dr. Yukiko Asada, who among many other things, has developed an innovative initiative to advance the science and practice of public deliberation that uses Lego Serious Play to engage people in expressing their ideas about hardship and what a good life entails. I have been an advisor to the project since its inception in January 2023 and will be joining as a collaborator this Fall. The visit gave us the opportunity to talk more in more depth about the project and for me to engage in a pilot session of FairLab with others.



Second, Yukiko arranged a small meeting with some of the researchers at the National Institutes of Minority Health and Health Disparities, which gave me the opportunity to share with them work I have begun to develop an ethical framework for intersectional health research. Intersectional health research examines health inequalities by multiple social group characteristics simultaneously and has been called “essential” to the explanation of health inequalities and advancement of health equity by the Director of the NIMHD, among others. I wanted to see if the framework, which was the paper I presented to the Department of Bioethics, resonated with people doing intersectional health research at the NIMHD.

Third, I also looked forward to meeting Dr. Wolff of Oxford University, whose work I have long followed and admired [editor’s note: Dr. Wolff also visited the department during Spring 2024]. We would walk every morning from the hotel where we both stayed to the NIH and talked about why and how we found our way to the work we each do, which shares an interest in questions of justice and respect for groups marginalized by social, economic, and political arrangements.

Q: What was your experience as a visiting scholar like?

Great fun is the simple answer. But in a serious vein, the visit was very meaningful. First, I had the opportunity to be a participant in a pilot session of FairLab, which meant I had the chance to express my ideas about hardship and the good life with Legos, which to date I had only done via my scholarship. I had never played with Legos before, which is a common childhood experience I am told. I loved it, and so did everyone else it seemed. When Yukiko first mentioned her idea of using Lego Serious Play as a means of expression in FairLab, I was immediately onboard. The idea of making things with your hands during deliberation had come up years earlier in collaborative work I was doing with Indigenous scholars and Tribal leaders to design and implement deliberations on questions of genomic research. One evening at dinner, after a deliberation in Alaska, we began to talk about using different techniques, in addition to spoken language, for participants to express themselves – beading, playdough, doodling, etc. We joked at the time that a paper could be titled, *From Plato to Playdough: Using Innovative Deliberative Methods with Tribal Communities* or something like that. Yukiko got there first with Legos!

Second, the meeting with NIMHD affirmed the direction I am heading with my work on intersectionality. The current state of intersectional health research faces an ever-growing list of social group characteristics that might serve as sources of disadvantage and health inequalities, raising a question about which among them matter and why. My framework aims to provide some guidance by describing these social characteristics in terms of the moral phenomena they represent, organizes them by type of social harm, and posits their moral status relative to another. The work draws on political philosopher Nancy Fraser’s social justice framework, which has long informed my scholarship and teaching.

Third, everyone during my stay was so welcoming. The department has wonderful traditions of hospitality and community that I think may be lost in some places. I love their “teatime” tradition. I drink a lot of herbal tea in the base case, but during that week my tea intake doubled.

Q: What have you been up to since your visit?

In addition to advancing the projects and papers just described, I have a new paper underway with colleagues at Harvard about the use of participatory and deliberative processes in healthcare settings. It will be part of a special collection of papers each of which will address some aspect of how to deliver on the promise of justice in American health care. I have also continued my collaborations with Indigenous scholars and Tribal communities. This work began some 7 years ago as a part of a NIH Center of Excellence called the Center for the Ethics of Indigenous Genomic Research (known as CEIGR) that was housed and directed at the University of Oklahoma. For the past several years, I have been collaborating with Drs. Nanibaa' Garrison (UCLA) and Katrina Claw (University of Colorado) and their teams to design and conduct deliberations about the cultural appropriateness of genomic research on Navajo Nation, which banned genomic research some 20+ years ago. That work was interrupted by the pandemic, but in late June we held two back-to-back deliberations over the course of one week on Navajo Nation. In late August, I headed east to Roanoke, VA, to spend time with Invest Health City Teams, which have been working to advance health equity by transforming how city leaders work together to help low-income communities thrive. I introduced the city teams to public deliberation and brainstormed with them about how to use it to drive collective decision-making.

Q: What's your favorite thing about being a bioethicist?

I get paid to think, write, talk about, and engage with a wide range of very thoughtful and smart people on issues we care about, and that we think are important social challenges. I have the opportunity to write about these issues, which I love. But I also get to lead, collaborate, and partner with others to develop resources (e.g., HealthCommons) and act in and on the world in a more direct way. The privilege of this work blows my mind. I think that is because this professional life is so distant from anything I was exposed to growing up. The people who reared me did not have high school degrees and were troubled; my childhood and teen years were riven by chaos, instability, poverty, and violence. I am deeply grateful to teachers, professors, colleagues, and other "life advisors" who helped light a pathway to a very different life.



2022-2024 FELLOW BIOGRAPHIES



Isabel Astrachan, BA Isabel received her BA from Brown University in 2022, where she double majored in Philosophy and Religious Studies. At the NIH, Isabel worked on topics related to decision-making capacity and medical aid-in-dying laws, as well as regulation of clinical trials. She is now attending Stanford Law School.



Ethan Bradley, BA: Ethan received a BA in Philosophy and Political Science from Oakland University. He has started PhD in philosophy at the University of Wisconsin–Madison. [editor's note: Go Badgers!]



Isabella Li, BS, BA: Isabella studied Molecular Biology and History of Medicine at Yale University. At the NIH, she analyzed methods to equitably engage underrepresented communities in clinical research, as well as interviewed patients and volunteers on their experiences at student-run free clinics. She is attending medical school at the University of Pennsylvania as a Twenty-First Century Scholar.



Elika Somani, BA: Elika graduated with a BA in Global Health and Development at Macalester College in 2021. Her work experience spans topics in global health and development, improving state governance, and institutional decision-making. At the NIH, she pursued projects around dual-use research of concern (DURC) and biosecurity governance and ethics. She has started a PhD program at RAND focusing on AI and biosecurity policy.



Aaron E. Segal, PhD: Aaron received his PhD in Philosophy from the University of Pittsburgh in 2022, where his dissertation investigated the nature of imperfect duties such as beneficence and gratitude. At the NIH, he worked on issues in research ethics related to the benefits and burdens of participating in medical research, including questions about research risks, compensation, fairness, and altruism. As of Fall 2024, he is Assistant Professor in the Department of Bioethics at Kansas City University.

Congratulations, fellows!

FACULTY & ALUMNI UPDATES

Will Smith: We are expecting our first child this December. Thrilled about it! We also moved to Chapel Hill for me to begin as an Asst Prof in UNC Psychiatry. Regarding work, I'm anticipating receiving a K award in the coming days to weeks for a trial of mHealth and incentive interventions in first-episode psychosis that focuses on implementation and ethics issues.

Sharona Hoffman: I have continued to serve as a Professor of Law and Bioethics at Case Western Reserve University. I have two forthcoming articles: S. Hoffman, "Employers and the Privatization of Public Health," 65:7 Boston College Law Review (2024) and S. Hoffman & C. Robertson, "Patient Autonomy, Public Safety, and Drivers with Cognitive Decline," 15 UC Irvine Law Review (2025). I also published S. Hoffman & A. Podgurski, "The Patient's Voice: Legal Implications of Patient-Reported Outcome Measures," 22 Yale Journal of Health Policy, Law, and Ethics 1-59 (2023). I was voted Teacher of the Year by the first-year law school class for the 2023-24 academic year. I have also continued my quest to see the world with trips to Portugal and Nova Scotia in the spring. Both are highly recommended!

Skye Miner: I started a position as an Associate Behavioral and Social Scientist at RAND in October 2023. I'm currently working on projects related to abortion policies and I am looking forward to integrating more empirical ethics research on genomic technologies and artificial intelligence into my research portfolio. I am living in Boston and am loving being able to walk to work.

Collin O'Neil: I co-authored a book on bioethics with two other alums of the NIH Department of Bioethics, Sean Aas and Chiara Lepora. Needless to say, our book was deeply influenced by the work of our former colleagues and mentors in the department. Here is a [link](#) to it.

Kathleen Fenton: Although not a big Halloween fan, I enjoy talking with people about death and especially ethical issues related to death. In this regard, I'm excited that my 2023 workshop on DCDD and xenotransplantation not only yielded several publications, but more importantly has resulted in NHLBI receiving a number of grant applications related to researching bioethical questions in death determination, and has led to many opportunities to discuss important (ethics) topics with colleagues and friends.

Dena S. Davis: Enjoying retirement in NYC, going to lots of dance and theater, playing lots of baroque music. Went to Kenya in February with a group from Center for Victims of Torture. eye-opening.

Yukiko Asada: In my second year, I continue to be very happy to be in my new academic home here at the NIH bioethics. For the past several months, I have been blessed with my new colleagues who eagerly volunteered to be pilot participants for FairLab What Makes a Good Life Study, a small group deliberation on good life and life hardships using LEGO as a thinking tool. Alex Welna, a new research assistant in the Department, is now an indispensable team member for the study.



Nir Eyal: In July 2024, stopped directing Rutgers's Center for Population-Level Bioethics, received a second endowed chair (now both Rutgers prof and Bergen prof of bioethics), and started a research leave in Oxford.

Rob Hughes: I am enjoying teaching business ethics at Rutgers Business School, and I continue to write about the ethics of exploitation. Matt and I now share our Hell's Kitchen apartment with an energetic 57-pound rescue dog.

Marie Nicolini: Starting September 2024, Marie Nicolini will take up a position as a joint faculty fellow at the Safra Center for Ethics at Harvard University and the Center for Bioethics at Harvard Medical School.

Sean Aas: Two pieces of good professional news: fellow Alumni Collin O'Neill and Chiara Lepora and I published a book - Bioethics: Fifty Puzzles and Problems. We hope it's a good resource for teaching and learning core cases in philosophical bioethics! It's available from the publisher (Routledge) and, no doubt, from all the finest booksellers. On another note, I was promoted to Associate Professor (with tenure) in the Philosophy Department (and Kennedy Institute of Ethics) at Georgetown. Looking forward to many more Joint Bioethics Colloquia!

George Rugare Chingarande, PhD: It has been an eventful year. I am working as a senior lecturer at Stellenbosch university, Faculty of Medicine and Health Sciences, Division of Medical Ethics and Law (Cape Town, South Africa). Besides teaching Medical Ethics modules to medical students, I am busy developing the curriculum and course content for an MPhil degree in Bioethics which will be offered in 2025. I also coordinated the development of a course on Responsible Conduct of Research, which is a requirement for scientists applying for NIH grants. The Health Professions Council of South Africa requires all healthcare workers to get at least 10 Ethics CPD points per year. To address this need we have been offering regular seminars on topical bioethics issues. My research focus is on ethical issues arising from Big Data with particular emphasis on Climate Change, Coloniality, Stakeholder Engagement and Health disparities and inequities (South Africa is the most unequal country in the world according to the Gini coefficient).



Bernardo Aguilera: Since 2021 I am a full time researcher in Bioethics at the Faculty of Medicine and Science at the Universidad San Sebastian, in Santiago, Chile. I recently completed a research grant funded by the Chilean National Research Agency on the Grounds of Moral Status and I have been engaged in several international collaborations, some including PAHO and NIH staff. Now I am also part of the expert group that is drafting the WHO guidance on Ethics and Health Research Priority Setting, led by Joe Millum. This year I plan to attend ASBH and I look forward to meeting some NIH colleagues in St Louis!

Aaron Segal: I'm starting a position as Assistant Professor in the Department of Bioethics at Kansas City University, where I'm continuing to think about risk, consent, and altruism. I'm quickly adjusting to life in the Midwest, with the help of great food, beer, and Royals baseball. I'm happy to say that Dave Wendler was right when he told me that Kansas City is a top five American city!

Jeff Sebo: I recently started a new position as Associate Professor of Environmental Studies at New York University, with affiliations in Bioethics, Medical Ethics, Philosophy, and Law. I also recently became Director of the Center for Environmental and Animal Protection, Founding Director of the Center for Mind, Ethics, and Policy, and Founding Co-Director of the Wild Animal Welfare Program at NYU. My previous book, *Saving Animals, Saving Ourselves*, will soon be released in open access, and my next book, *The Moral Circle*, will be out in January. Among other projects, I co-organized the New York Declaration on Animal Consciousness in 2024; the declaration, which attributes a realistic chance of consciousness to all vertebrates and many invertebrates, was signed by hundreds of scholars and covered in hundreds of outlets.



Sophie Gibert: I'm graduating from MIT this month with my PhD in philosophy, and I start as a Bersoff Fellow at NYU in September. Next fall I'll be an assistant professor at the Wharton School, where I look forward to reconnecting with the many former fellows and affiliates scattered around Penn.

Matthew Morgado: I've been blessed to have met and married my significant other. We were married about two-and-a-half months ago in South Korea, where she is from. I'm continuing in the Philosophy Program here at Johns Hopkins, enjoying the challenges and experiences of the program. I've so far TA-ed our large Bioethics course twice. My NIH Bioethics training proved invaluable in helping students through the course. I'm thankful every day for my wonderful experiences at the Department of Bioethics, and I look forward to how the Department will shape bioethics research in the years to come.