# Leila Jamal, ScM, PhD, LGC (347) 327-0104 | <u>leila.jamal@nih.gov</u> | ORCID: 0000-0003-1132-2411

### **Summary of Qualifications**

Certified genetic counselor with clinical experience in neurology, oncology, and immunology

Doctoral degree in social scientific research methods and applied/normative ethics

Extensive teaching, mentoring, and curriculum design experience at the graduate level

Experience in clinical ethics consultation and institutional review board service

#### **Current Positions**

2020-present

Associate Director for Cancer Genomics

Johns Hopkins University/NIH Genetic Counseling Training Program

2020-present

Genomics Education Specialist (GS-13)

National Cancer Institute

2022-present

Adjunct Faculty

NIH Clinical Center Department of Bioethics

2020-present

Adjunct Assistant Professor

Department of Health, Behavior, and Society

Johns Hopkins Bloomberg School of Public Health

#### **Education**

2011-2017

Ph.D. in Bioethics and Health Policy

Department of Health Policy and Management

Johns Hopkins Bloomberg School of Public Health Baltimore, MD

2009-2012

Sc.M. in Genetic Counseling

Department of Health, Behavior and Society

Johns Hopkins Bloomberg School of Public Health Baltimore, MD

1999-2002

B.A. (M.A., Oxon) in Philosophy, Politics, and Economics

St. John's College

University of Oxford, Oxford, United Kingdom

# **Postdoctoral + Other Research Experience**

2019-2022

Affiliated Scholar

NIH Department of Bioethics

2017-2018

Hecht-Levi Postdoctoral Fellow

Johns Hopkins Berman Institute of Bioethics Baltimore, MD

2014-2017

Research Assistant II

Baylor College of Medicine Center for Medical Ethics and Health Policy Houston, TX (remote, part-time position)

# **Clinical Experience**

2024-present

Attending Bioethicist

NIH Clinical Center Bioethics Consult Service

2017-2020

Genetic Counselor,

National Institute of Allergy and Infectious Diseases (NIAID)

Associate Investigator,

NIAID Centralized Sequencing Initiative

National Institutes of Health, Bethesda, MD

2015-2017

Genetic Counselor,

Division of Human Genetics (Oncology)

University of Maryland Baltimore, MD

2012-2014

Genetic Counselor,

Division of Neurogenetics

Kennedy Krieger Institute Baltimore, MD

#### **Professional Service**

2024-Present

Associate Editor, Editorial Board, Journal of Genetic Counseling (Ethics Lead)

2024-Present

Vice Chair, Diversity, Equity, and Inclusion Committee, Genetic Counseling Educators' Association (GCEA)

2021-2023

Director-at-Large, Board of Directors, National Society of Genetic Counselors

2019-Present

Member (Scientist), NIH Centralized Institutional Review Board

2023-2025

Member, Genetic Counseling Resource Advisory and Advocacy Board Genetic Counseling Resource, AllofUS

2023

Co-chair, Public Policy Committee Maryland and DC Society of Genetic Counselors

2021-2023

Director-at-Large, Board of Directors, National Society of Genetic Counselors

[Information about additional service roles available on request]

### **Professional Certifications + Licenses**

2024-present

Maryland Board of Physicians Genetic Counseling State Licensure

2013-Present

American Board of Genetic Counseling Certification

#### **Professional Certifications + Licenses**

2023

Ann Krush Memorial Lectureship, Collaborative Group of the Americas on Inherited Gastrointestinal Cancer

• Lecture Topic: Genetic Risk Assessment Across the Lifespan

2019

NIAID Director's Award, National Institutes of Health

• Awarded for developing a clinical genomics platform comprised of centralized sequencing and novel systems for collaborative and integrative data analysis and mining to understand immunogenetic disorders

2018

NIAID Merit Award, National Institutes of Health

• Awarded for co-creating a collaborative community of research groups within NIH, leading to research that advances the development of precision medicine treatments

[Information about additional honors and awards available on request]

# Selected Peer-Reviewed Publications and Commentaries (mentees underlined)

- 1. <u>Davidson HR</u>, **Jamal L**, Mueller R, Similuk M, Owczarzak J. Renegotiation, uncertainty, imagination: Assemblage perspectives on reproductive and family planning with an Inborn Error of immunity. Soc Sci Med. 2024 Sep 6;360:117303. doi: 10.1016/j.socscimed.2024.117303. Epub ahead of print. PMID: 39265231.
- 2. Platt DM, Blout Zawatsky CL, Christensen KD, Green RC, Hajek C, Hickingbotham MR, Hutchinson AM, LeBlanc JL, Zoltick ES, **Jamal** L. Primary Care Providers' Experiences With an Active Elective Genetic Testing Program. Health Educ Behav. 2024 Jul 30:10901981241266849. doi: 10.1177/10901981241266849. PMID: 39081055.
- 3. **Jamal L**, Zayhowski K, Berro T, Baker K. Queering genomics: How cisnormativity undermines genomic science. HGG Adv. 2024 Jul 18;5(3):100297. doi: 10.1016/j.xhgg.2024.100297. Epub 2024 Apr 17. PMID: 38637989; PMCID: PMC11129102.
- 4. Roth S, Owczarzak J, Baker K, Davidson H, **Jamal L.** Experiences of hereditary cancer care among transgender and gender diverse people: "It's gender. It's cancer risk...it's everything". J Genet Couns. 2024 Feb 11. doi: 10.1002/jgc4.1867. PMID: 38342966; PMCID: PMC11316848.
- 5. Sweeney J, Tichnell C, Christian S, Pendelton C, Murray B, Roter DL, Jamal L, Calkins H, James CA. Characterizing Decision-Making Surrounding Exercise in ARVC: Analysis of Decisional Conflict, Decisional Regret, and Shared Decision-Making. Circ Genom Precis Med. 2023 Dec;16(6):e004133. doi: 10.1161/CIRCGEN.123.004133. Epub 2023 Nov 28. PMID: 38014565; PMCID: PMC10729899.
- 6. Zierhut H, **Jamal L**, Riordan S, Wilson P, Carey M, Babu D. National Society of Genetic Counselors' Board of Directors response to Myers et al. 'A report of the AGCPD task force to evaluate associations between select admissions requirements, demographics, and performance on ABGC certification examination'. J Genet Couns. 2022 Apr;31(2):319-323. doi: 10.1002/jgc4.1569. Epub 2022 Mar 8. PMID: 35263009; PMCID: PMC9311064.
- 7. **Jamal** L, May M, Setzer MR, Yu M, Berkman B, Similuk M. Research participants' perspectives about the return of uninformative genomic test results in a clinical research setting. J Genet Couns. 2023 Aug 28. PMID: 37641538; PMCID: PMC10899523.
- 8. <u>Miner SA</u>, Similuk M, **Jamal L**, Sapp J, Berkman BE. Genomic tools for health: Secondary findings as findings to be shared. Genet Med. 2022 Aug 18:S1098-3600(22)00866-8. doi: 10.1016/j.gim.2022.07.015. PMID: 35980380; PMCID: PMC9643624.
- 9. <u>Miner SA</u>, Berkman BE, Altiery de Jesus V, Jamal L, Grady C. Navigating Pandemic Moral Distress at Home and at Work: Frontline Workers' Experiences. AJOB Empir Bioeth. 2022 Oct-Dec;13(4):215-225. doi: 10.1080/23294515.2022.2064000. Epub 2022 Apr 26. PMID: 35472000.

- 10. Berkman BE, Mastroianni AC, **Jamal L**, Solis C, Taylor HA, Hull SC. The Ethics of Repurposing Previously Collected Research Biospecimens in an Infectious Disease Pandemic. Ethics Hum Res. 2021 Mar;43(2):2-18. PMID: 36715254.
- 11. Christensen KD, Bell M, Zawatsky CLB, Galbraith LN, Green RC, Hutchinson AM, **Jamal L**, LeBlanc JL, Leonhard JR, Moore M, Mullineaux L, Petry N, Platt DM, Shaaban S, Schultz A, Tucker BD, Van Heukelom J, Wheeler E, Zoltick ES, Hajek C; Imagenetics Metrics Team. Precision Population Medicine in Primary Care: The Sanford Chip Experience. Front Genet. 2021 Mar 12;12:626845. doi: 10.3389/fgene.2021.626845. PMID: 33777099; PMCID: PMC7994529.
- 12. <u>Schupmann W, Jamal L, Berkman BE. Re-examining the Ethics of Genetic Counselling in the Genomic Era. J Bioeth Inq. 2020 Sep;17(3):325-335. doi: 10.1007/s11673-020-09983-w. Epub 2020 Jun 15. PMID: 32557217; PMCID: PMC10084396.</u>
- 13. **Jamal L**, Schupmann W, Berkman BE. An ethical framework for genetic counseling in the genomic era. J Genet Couns. 2020 Oct;29(5):718-727. doi: 10.1002/jgc4.1207. Epub 2019 Dec 19. PMID: 31856388; PMCID: PMC7302959.
- 14. Bombard Y, Brothers KB, Fitzgerald-Butt S, Garrison NA, **Jamal L**, James CA, Jarvik GP, McCormick JB, Nelson TN, Ormond KE, Rehm HL, Richer J, Souzeau E, Vassy JL, Wagner JK, Levy HP. The Responsibility to Recontact Research Participants after Reinterpretation of Genetic and Genomic Research Results. Am J Hum Genet. 2019 Apr 4;104(4):578-595. doi: 10.1016/j.ajhg.2019.02.025. PMID: 30951675; PMCID: PMC6451731.
- 15. **Jamal** L, Robinson JO, Christensen KD, Blumenthal-Barby J, Slashinski MJ, Perry DL, Vassy JL, Wycliff J, Green RC, McGuire AL. When bins blur: Patient perspectives on categories of results from clinical whole genome sequencing. AJOB Empir Bioeth. 2017 Apr-Jun;8(2):82-88. PMID: 28949844; PMCID: PMC6647021.
- 16. Christensen KD, Vassy JL, **Jamal L**, Lehmann LS, Slashinski MJ, Perry DL, Robinson JO, Blumenthal-Barby J, Feuerman LZ, Murray MF, Green RC, McGuire AL. Are physicians prepared for whole genome sequencing? a qualitative analysis. Clin Genet. 2016 Feb;89(2):228-34. PMID: 26080898; PMCID: PMC4683111.
- 17. Lupo PJ, Robinson JO, Diamond PM, **Jamal L**, Danysh HE, Blumenthal-Barby J, Lehmann LS, Vassy JL, Christensen KD, Green RC, McGuire AL. Patients' perceived utility of whole-genome sequencing for their healthcare: findings from the MedSeq project. Per Med. 2016 Jan 1;13(1):13-20. PMID: 27019659; PMCID: PMC4806392.
- 18. Angrist M, **Jamal** L. Living laboratory: whole-genome sequencing as a learning healthcare enterprise. Clin Genet. 2015 Apr;87(4):311-8. PMID: 25045831; PMCID: PMC4302048.
- 19. Hercher L, **Jamal** L. An old problem in a new age: Revisiting the clinical dilemma of misattributed paternity. Appl Transl Genom. 2016 Feb 1;8:36-9. doi: 10.1016/j.atg.2016.01.004. PMID: 27047759; PMCID: PMC4796701.
- 20. **Jamal** L, Sapp JC, Lewis K, Yanes T, Facio FM, Biesecker LG, Biesecker BB. Research participants' attitudes towards the confidentiality of genomic sequence information. Eur J Hum Genet. 2014 Aug;22(8):964-8. PMID: 24281371; PMCID: PMC4350593.

21. Mathews DJ, **Jamal** L. Revisiting respect for persons in genomic research. Genes (Basel). 2014 Jan 22;5(1):1-12. PMID: 24705284; PMCID: PMC3978508.

[Additional peer-reviewed publications available via Google Scholar, ORCID, or by request]

#### **Selected Conference Presentations**

- 1. 2024 Invited Panel Presentation, "Exceptional Injustice: Interrogating Public Comments about Migrant DNA Collection at the Border" (w/Rachel Fabi and Liz Dietz)
- 2. 2024 Invited Panel Presentation, "Just Because We Can, Should We? Examining Pre-Implantation Genetic Testing Through the Lenses of Ableism, Ethics, and Actionability" (w/Meghan Bombalicki, Courtney Studwell, Sara Levene, Gina Londre, and Samantha Stover)
- 3. 2023 Paper Presentation, "A Normative Justification for Health System-Led Notification of Relatives Eligible for Cascade Screening", American Society of Bioethics and Humanities Annual Meeting
- 4. 2023 Anne Krush Invited Lecturer, "Counseling of Children for Adult-Onset Conditions", Collaborative Group of the Americas on Inherited Gastrointestinal Cancer
- 5. 2023 Invited Panel Presentation, "Genetic Counselors' Perspectives on Polygenic Embryo Screening" (w/Hannah Wand, Katie Stoll, and Laura Hercher), Ready or Not? The Science and Ethics of Polygenic Embryo Selection
- 6. 2022 –Panel Presentation, "Implementation Science for Genetic Counselors: Tools to improve equity and engagement in your practice", (w/ Alanna Rahm, Amy Sturm, Eric Tricou, Elissa Levin, and Hannah Wand), National Society of Genetic Counselors' Annual Conference
- 7. 2022 –Panel Presentation, "Depathologizing Sex and Gender Diversity in Genetic Counseling" (w/Kimberly Zayhowski, Tala Berro, and Kellan Baker), National Society of Genetic Counselors' Annual Conference
- 8. 2022 –Panel Presentation, "Beyond the Binary: A Panel Discussion about Gender, Genomics, and Justice" (w/Kimberly Zayhowski, Tala Berro, and Kellan Baker), ELSI Congress
- 9. 2022 –Panel Presentation, "Choice Architecture in Genetics and Genomics: Where Have We Been and Where Are We Going?" (w/Susanna McGrew and Benjamin Berkman), ELSI Congress
- 10. 2022 Speaker, "Genetic Counseling and Public Health Ethics" Massachusetts General Hospital Genetic Counseling Training Program
- 11. 2022 Speaker, "Using Influence and Persuasion in Genetic Counseling", Bioinformatics and Human Genetics Seminar Series, UCLA

- 12. 2021 Moderator, "Leveraging the Power of AI and Electronic Health Records" at the American Society of Human Genetics Annual Conference
- 13. 2021 Pre-Conference Symposium, "A Grant Writing Retreat to Jump Start Your Proposal" at the National Society of Genetic Counselors' Annual Conference
- 14. 2021 Educational Breakout Session, "To Tell or Not To Tell: 'Tis the Question. Returning Information About Adult-Onset Cancer Risk to Minors" at the National Society of Genetic Counselors' Annual Conference
- 15. 2021 Invited Plenary Speaker, "Directiveness in Genetic Counseling: Navigating our Shared Future with Values, Evidence, and Versatility" at the National Society of Genetic Counselors' Annual Conference
- 16. 2021 Invited Guest Speaker, Panel Presentation on "Ethical Issues Related to Precision Oncology" at the Oncology Nursing Society Annual Conference
- 17. 2021 Invited Guest Speaker, Panel Presentation on "Paternalism in Genetics" at NHGRI
- 18. 2020 "Re-thinking the Role of Ethics in Genetic Counseling Practice" at the Maryland and DC Society of Genetic Counselors' Annual Meeting

[Information about additional presentations available by request]

# **Teaching and Course Development Experience**

2024-present – Preceptor, PROMOTE-GC Training Program for Advanced Research Education of Genetic Counselors, Johns Hopkins University School of Medicine

 Developed and delivered three instructional modules covering Qualitative Research Methods, Mixed Methods Research, and Applications of Ethical Theories to Genetic Counseling Research

2022-present - Graduate Instructor + Course Designer, Cancer Standardized Patient Rotation, National Institutes of Health and Johns Hopkins Bloomberg School of Public Health

• Designed, precepted, evaluated an 8-week cancer genetic counseling course involving eight simulated genetic counseling sessions for six students; scripted all of the simulations, and taught a clinical skills class in conjunction with the simulations. I teach this course annually.

2021-present – Graduate Instructor + Course Designer, Precision Oncology, National Institutes of Health

• Designed and delivered four short, asynchronous lectures addressing emerging technologies used for genetic cancer risk assessment. I teach this course annually.

2020-present – Graduate Instructor, Introduction to Genetic Counseling II, Johns Hopkins Bloomberg School of Public Health

- Re-designed and taught the second quarter of Introduction to Genetic Counseling, a first-year genetic counseling course examining systemic, historical, and sociocultural influences on the genetic counseling profession. I teach this course annually.
- [Information about additional teaching roles available on request]

## **Student Advising**

- 2024-2026 Thesis Advisor, Hannah Miller, Johns Hopkins/NIH Genetic Counseling Training Program
- 2023-2025 Co-Advisor, Emily Peugh, NIH Bioethics Department Postbaccalaureate Fellow
- 2023-2024 Thesis Advisor, Olivia Dobbie, Johns Hopkins/NIH Genetic Counseling Training Program
- 2023-2024 Thesis Committee Member, Jennifer Osborne, Johns Hopkins/NIH Genetic Counseling Training Program
- 2022-2023 Thesis Co- Advisor, Emma Schopp, Johns/Hopkins/NIH Genetic Counseling Training Program
- 2022-2023 Thesis Advisor, Liam Guille, Johns Hopkins/NIH Genetic Counseling Training Program
- 2021-2022- Thesis Advisor, Emerald Kaitlyn, Johns Hopkins/NIH Genetic Counseling Training Program
- 2021-2022 Thesis Advisor, Sarah Roth, Johns Hopkins/NIH Genetic Counseling Training Program
- 2020-2021 Thesis Advisor, Wes Solem, Johns Hopkins/NIH Genetic Counseling Training Program
- 2020-2021 Thesis Advisor, Jalisa Decker, Johns Hopkins/NIH Genetic Counseling Training Program
- 2019-2020 Thesis Committee Member, Emma Moores, University of Maryland Genetic Counseling Training Program
- 2018-2020-Clinical Supervisor, Johns Hopkins/NHGRI Genetic Counseling Training program
- 2017-2018 Thesis Committee Member, Xin Li, University of Maryland Genetic Counseling Training Program
- 2016-2017 Clinical Supervisor, University of Maryland Genetic Counseling Training Program

2015 - Thesis Committee Member, Jenn Kohler, Johns Hopkins/NHGRI Genetic Counseling Training Program

## **Skills + Training**

Certificate in Race, Diversity, and Equity in Higher Education, University of Pennsylvania School of Graduate School of Education (2023)

City of Hope Intensive Course in Genetic Cancer Risk Assessment (Track 2, Class of 2021) Certified Pilates Instructor (500h) with additional training in Pilates for neurological conditions NSGC Leadership Trainee (2017-2018)

Statistical analysis (using STATA and SPSS) Qualitative data analysis (using NVivo and MaxQDA)

Grant Writers' Seminars and Workshops - NIH Version (2014)

## **Professional Society Memberships**

National Society of Genetic Counselors
Association of Genetic Counseling Program Directors
American Society of Human Genetics
American Society for Bioethics and Humanities
Collaborative Group of the Americas on Inherited Colorectal Cancer (CGA-ICC)

## Citizenship

United States and United Kingdom