The National Academies of
SCIENCES • ENGINEERING • MEDICINE

Board on Health Sciences Policy

Roundtable on Genomics and Precision Health

Fall 2021 Workshop

October 5, 2021 (12 PM – 3:30 PM ET)

Webcast link:
https://www.nationalacademies.org/event/10-05-2021/improving-diversity-of-the-genomics-workforce-a-workshop

*Questions for speakers can be submitted in the box under the webcast on this site

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AGENDA

The National Academies of
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Board on Health Sciences Policy
Roundtable on Genomics and Precision Health

Roundtable on Genomics and Precision Health

Improving Diversity of the Genomics Workforce: A Workshop

A Virtual Workshop
October 5, 2021
12:00 PM – 3:30 PM ET

Webcast link:
https://www.nationalacademies.org/event/10-05-2021/improving-diversity-of-the-genomics-workforce-a-workshop

STATEMENT OF TASK:
A planning committee of the National Academies of Sciences, Engineering, and Medicine will organize and conduct a public workshop to examine the current state of diversity (e.g. racial, ethnic) of the genetics and genomics workforce, the factors that have contributed and are contributing to the diversity challenges, and possible steps forward that could lead to increasing workforce diversity as a way to improve access to genomic services.

The workshop will feature invited presentations and discussions that may address topics such as:

- Historical perspectives on racism and its impacts on the culture of the fields of genetics and genomics;
- Ways in which the genetics/genomics workforce is or is not uniquely affected by structural racism;
- Current and ongoing workforce diversity efforts of genetics/genomics professional organizations and other groups;
- Implications of diversifying the workforce for patient care and access to genomic services; and
- Next steps and roles for institutions, societies, associations, community organizations, and other stakeholders for fostering diversity, equity, and inclusion in this area.

A proceedings in brief of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

12:00 pm **Welcoming Remarks**

MICHELLE PENNY, *Roundtable Co-Chair*
Vice President and Head of Genomics
Goldfinch Bio

W. GREGORY FEERO, *Roundtable Co-Chair*
Representing Journal of the American Medical Association
Professor, Department of Community and Family
Medicine, Geisel School of Medicine
Faculty, Maine Dartmouth Family Medicine Residency Program

12:05 pm **Introduction and Charge to the Workshop Speakers and Participants**

CHAZEMAN JACKSON, *Workshop Planning Committee Co-chair*
Senior Director, Diversity Equity and Inclusion
American Society of Human Genetics

KATHERINE JOHANSEN TABER, *Workshop Planning Committee Co-chair*
Vice President, Clinical Product Research & Partnerships
Myriad Genetics

SESSION I: EXPLORING WORKFORCE DIVERSITY ISSUES IN GENETICS/GENOMICS

Moderator: Jacquelyn Taylor, Helen F. Petit Professor of Nursing, Founder and Executive Director, Center for Research on People of Color, Columbia University School of Nursing

Session Objectives:

- To examine the fundamental structural challenges that have resulted in a lack of diversity in the genetics/genomics workforce and explore new opportunities for change.
- To discuss action-oriented efforts of medical and genetics professionals related to workforce diversity and consider how those efforts will attempt to address the structural issues facing the community.

12:10 pm **Overview of Workforce Issues in Genetics/Genomics**

Barbara Harrison
Genetic Counselor
Assistant Professor
Department of Pediatrics
Howard University College of Medicine

Sylvia Mann
Supervisor, Genomics Section
State of Hawaii Department of Health
Director, Western States Regional Genetics Network
Minority Genetic Professionals Network

Omar Abdul-Rahman
Director of Genetic Medicine
Munroe-Meyer Institute
University of Nebraska Medical Center

1:15 pm **Discussion**

1:35pm **Break**

SESSION II: LEARNING FROM THOSE IN THE GENETICS/GENOMICS COMMUNITY

Moderator: Sharon Terry, President and CEO, Genetic Alliance

Session Objective:

- To explore the relationship between the lack of diversity in the workforce and patient access to genetic services, understand why workforce diversity matters for patient care, and examine the ways in which professional societies and associations can make a difference in this area.

1:55 pm **Voices From the Community**
Improving diversity and impact on outcomes for patients

Altovise Ewing
Senior Science Leader
Genentech

Damian Archer
Assistant Dean for Multicultural Affairs
Clinical Assistant Professor of Family Medicine
Tufts University School of Medicine
With

Dallas Reed
Division Chief of Genetics
Tufts Children's Hospital
Director of Perinatal Genetics
Tufts Medical Center

LaTasha Lee
Vice President
Clinical & Social Research and Development
National Minority Quality Forum

Catalina Sol
Executive Director
La Clinica del Pueblo

2:50 pm **Panel Discussion**

3:15 pm **Reflections from the Workshop and Final Comments**

CHAZEMAN JACKSON, *Workshop Planning Committee Co-chair*
Senior Director, Diversity Equity and Inclusion
American Society of Human Genetics

KATHERINE JOHANSEN TABER, *Workshop Planning Committee Co-chair*
Vice President, Clinical Product Research & Partnerships
Myriad Genetics

3:30 pm **Adjourn Workshop**

GENOMICS ROUNDTABLE INFORMATION

The National Academies of
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Roundtable on GENOMICS and PRECISION HEALTH

The sequencing of the human genome is rapidly opening new doors to research and progress in biology, medicine, and health care. At the same time, these developments have produced a diversity of new issues to be addressed.

The National Academies of Sciences, Engineering, and Medicine has convened a Roundtable on Genomics and Precision Health (previously the Roundtable on Translating Genomic-Based Research for Health) that brings together leaders from academia, industry, government, foundations and associations, and representatives of patient and consumer interests who have a mutual concern and interest in addressing the issues surrounding the translation of genome-based research for use in maintaining and improving health. The mission of the Roundtable is to advance the field of genomics and improve the translation of research findings to health care, education, and policy. The Roundtable will discuss the translation process, identify challenges at various points in the process, and discuss approaches to address those challenges.

The field of genomics and its translation involves many disciplines, and takes place within different economic, social, and cultural contexts, necessitating a need for increased communication and understanding across these fields. As a convening mechanism for interested parties from diverse perspectives to meet and discuss complex issues of mutual concern in a neutral setting, the Roundtable: fosters dialogue across sectors and institutions; illuminates issues, but does not necessarily resolve them; and fosters collaboration among stakeholders.

To achieve its objectives, the Roundtable conducts structured discussions, workshops, and symposia. Workshop summaries will be published and collaborative efforts among members are encouraged (e.g., journal articles). Specific issues and agenda topics are determined by the Roundtable membership, and span a broad range of issues relevant to the translation process.

Issues may include the integration and coordination of genomic information into health care and public health including encompassing standards for genetic screening and testing, improving information technology for use in clinical decision making, ensuring access while protecting privacy, and using genomic information to reduce health disparities. The patient and family perspective on the use of genomic information for translation includes social and behavioral issues for target populations. There are evolving requirements for the health professional community, and the need to be able to understand and responsibly apply genomics to medicine and public health.

Of increasing importance is the need to identify the economic implications of using genome-based research for health. Such issues include incentives, cost-effectiveness, and sustainability.

Issues related to the developing science base are also important in the translation process. Such issues could include studies of gene-environment interactions, as well as the implications of genomics for complex disorders such as addiction, mental illness, and chronic diseases.

Roundtable sponsors include federal agencies, pharmaceutical companies, medical and scientific associations, foundations, and patient/public representatives. For more information about the Roundtable on Genomics and Precision Health, please visit our website at nationalacademies.org/GenomicsRT or contact Sarah Beachy at 202-334-2217, or by e-mail at sbeachy@nas.edu.

500 Fifth Street, NW, Washington, DC 20001
Phone 202.334.2217 E-mail sbeachy@nas.edu nationalacademies.org/GenomicsRT

Roundtable on Genomics and Precision Health Membership

W. Gregory Feero, M.D., Ph.D. (Co-Chair) *JAMA*
Michelle Penny, Ph.D. (Co-Chair) Goldfinch Bio

Naomi Aronson, Ph.D.
BlueCross/BlueShield Association

Aris Baras, M.D., M.B.A.
Regeneron Pharmaceuticals

Vence Bonham, Jr., J.D.
National Human Genome Research Institute

Bernice Coleman, Ph.D., ACNP-BC, FAHA, FAAN,
American Academy of Nursing

Robert B. Darnell, M.D. Ph.D.
The Rockefeller University / NY Genome Center

Stephanie Devaney, Ph.D.
All of Us Research Program, NIH

Geoffrey Ginsburg, M.D., Ph.D.
Global Genomic Medicine Collaborative (G2MC)

Jennifer Goldsack, MChem, M.A., M.B.A.,
Digital Medicine Society (DiMe)

Eric Gustafson, Ph.D.,
Merck & Co.

Jill Hagenkord, M.D., FCAP
Optum Genomics

Richard Hodes, M.D.
National Institute on Aging

Geoff Hollett, Ph.D.
American Medical Association

Mira Irons, M.D.
College of Physicians Philadelphia

Praduman Jain, M.S.
Vibrent Health

Sekar Kathiresan, M.D.
Massachusetts General Hospital

Muin Khoury, M.D., Ph.D.
Centers for Disease Control and Prevention

Charles Lee, Ph.D., FACMG
The Jackson Laboratory for Genomic Medicine

James Lu, M.D., Ph.D.
Helix

Christa Lese Martin, Ph.D., FACMG
Geisinger

Mona Miller, M.P.P.
American Society of Human Genetics

Adele Mitchell, Ph.D.
Biogen

Jennifer Moser, Ph.D.
U.S. Department of Veterans Affairs

Maximilian Muenke, M.D., FACMG
American College of Medical Genetics and Genomics

Susan E. Old, Ph.D.
National Institute of Nursing Research

Kathryn Phillips, Ph.D.
University of California, San Francisco

Victoria M. Pratt, Ph.D., FACMG
Association for Molecular Pathology

Murray Ross, Ph.D.
Kaiser Foundation Health Plan, Inc.

Wendy Rubinstein, M.D., Ph.D.
Food and Drug Administration

Nadeem Sarwar, Ph.D.
Eisai Inc.

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Health Resources and Services Administration

Sam Shekar, M.D., M.P.H.
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Nonniekaye Shelburne, C.R.N.P., M.S., A.O.C.N.,
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Geetha Senthil, Ph.D.
National Institute of Mental Health

Nikoletta Sidiropoulos, M.D.
University of Vermont Health Network Medical Group

Katherine Johansen Taber, Ph.D.
Myriad Genetics

Ryan Taft, Ph.D.,
Illumina

Jacquelyn Taylor, Ph.D.
Columbia University

Sharon Terry, M.A.
Genetic Alliance

Joyce Tung, Ph.D.
23andMe, Inc.

Jameson Voss, M.D.
U.S. Air Force

Karen Weck, M.D.
College of American Pathologists

Catherine A. Wicklund, M.S., C.G.C.
National Society of Genetic Counselors

Huntington F. Willard, Ph.D.
Geisinger National Precision Health

Sarah Wordsworth, Ph.D.
University of Oxford

Alicia Zhou, Ph.D.
Color Genomics

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Sarah H. Beachy, Ph.D., *Roundtable Director*
Kathryn Asalone, Ph.D., *Associate Program Officer*
Samantha Schumm, Ph.D., *Associate Program Officer*
Meredith Hackmann, *Associate Program Officer*
Lydia Teferra, *Research Assistant*

VISION	**Realizing the full potential of health for all through genomics and precision health.**
MISSION	**We bring together diverse voices to encourage innovation and actions that foster the wide adoption of and equitable access to the benefits of genomics and precision health.**

As a group of committed stakeholders, we believe in…

- Creating an inclusive and optimistic environment for discussion
- Learning from successes and missteps in the field
- Demanding reproducible evidence-based science
- Sharing trustworthy information
- Embracing interdisciplinary strategies
- Optimizing data privacy and security
- Advancing health equity in all that we do

The Roundtable focuses its energy and resources on these priorities:

DRIVE **INNOVATION** IN GENOMICS AND PRECISION HEALTH	Identify the competing barriers and facilitators of innovation for genomics-based diagnostics, risk assessment tools, and therapies. Leverage opportunities to learn from and promote innovative approaches that can accelerate commercialization and integration to drive impact of genomics on precision health.
SPUR THE **ADOPTION** OF GENOMICS-BASED TOOLS AND PRECISION HEALTH APPROACHES	Cultivate evidence-based practices across the health care and public health systems for adopting genomics and precision health. Draw attention to gaps in adoption and their root causes and highlight potential solutions.
ACHIEVE **EQUITY** IN GENOMICS AND PRECISION HEALTH	Foster action related to underrepresentation and inequities in genomic research, workforce, and access to genomic services by people who need them. Look internally to improve the processes and practices the Roundtable employs to achieve its mission.
SHAPE THE **POLICY DIALOGUE** ABOUT GENOMICS AND PRECISION HEALTH	Accelerate the dissemination of actionable knowledge to shape practice and increase public awareness. Inform and influence how decisions are made.

DEFINITIONS

Precision Health | Inclusive of precision medicine, precision health is a broader, proactive and people-focused approach to health, relying on individual-focused care and everyday decision-making to better predict, prevent, and treat disease.

Genetics | Study of heredity, genes, and genetic variation.

Genomics | Study of the genome by using DNA sequencing and other technologies to understand gene structure, function, and regulation.

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Board on Health Sciences Policy
Roundtable on Genomics and Precision Health

Membership Roster

W. Gregory Feero, M.D., Ph.D. *(Co-Chair)*
(*Representing Journal of the American Medical Association*)
Professor, Department of Community and Family Medicine, Geisel School of Medicine
Faculty, Maine Dartmouth Family Medicine Residency Program

Michelle Penny, Ph.D. *(Co-Chair)*
Vice President & Head of Genomics
Goldfinch Bio

Naomi Aronson, Ph.D.
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Aris Baras, M.D., M.B.A.
Senior Vice President
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General Manager
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Vice President, Head of Genome Informatics & Data Engineering
Regeneron Pharmaceuticals

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Board on Health Sciences Policy

SAVE THE DATE!

Realizing the Full Potential of Health for All Through Genomics and Precision Health:
A discussion with the National Academies Genomics Roundtable

An Ancillary Event to ASHG's Annual Meeting

A Virtual Meeting
October 20, 2021
7:00 – 8:00 PM ET
Zoom Webinar Link: TBD

AGENDA:

7:00 pm ET **Welcoming Remarks**

GEOFFREY GINSBURG, M.D., PH.D.
Director, Duke Center for Applied Genomics & Precision Medicine
Professor, Medicine, Pathology, and Biomedical Engineering
Duke University Medical Center

7:05 pm **Keynote Talk**

VENCE BONHAM, JR, J.D.
Acting Deputy Director
National Human Genome Research Institute
National Institutes of Health

7:20 pm **How Equity Can Enable Adoption and Innovation**

MIRA IRONS, M.D.
President and CEO
College of Physicians of Philadelphia

JOYCE TUNG, PH.D.
Vice President, Research
23andMe

7:30 pm **Getting Involved in the Roundtable's Work**
SARAH BEACHY, PH.D.
Director, Roundtable on Genomics and Precision Health
Board on Health Sciences Policy
The National Academies of Sciences, Engineering, and Medicine

7:30 pm **Questions and Open Dialogue with the Community**
Moderated by: Geoffrey Ginsburg

7:55 pm **Closing Comments**

8:00 pm **Meeting Adjourns**

WORKSHOP INFORMATION

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Improving Diversity of the Genomics Workforce: A Workshop

Planning Committee Members

Chazeman Jackson (Co-Chair), American Society of Human Genetics

Katherine Johansen Taber (Co-Chair), Myriad Genetics

Vence Bonham, National Human Genome Research Institute

Neil Hanchard, National Human Genome Research Institute

Erica Ramos, Genome Medical

Sharon Terry, Genetic Alliance

Catherine Wicklund, Northwestern University

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Improving Diversity of the Genomics Workforce: A Workshop

Planning Committee Member Biographies

Chazeman S. Jackson (co-chair), Ph.D., M.A., the Senior Director, Diversity, Equity & Inclusion of the American Society of Human Genetics, is an experienced health science researcher, public health administrator, and seasoned policy advisor. Most recently, Dr. Jackson served as a senior science policy analyst and the lead for the National Institutes of Health portfolio within the Office of the Assistant Secretary for Planning and Evaluation at the U.S. Department of Health and Human Services. Dr. Jackson joined the department in 2010 as an Emerging Leader Fellow and a health science administrator at the National Institute on Minority Health and Health Disparities. From 2012 - 2016, she played an essential role, as health science advisor, developing and implementing the HHS Office of Minority Health's research and science policy agenda. Dr. Jackson earned a Bachelor of Arts degree in humanities with an emphasis in philosophy from Tougaloo College, a Master of Arts degree in biology from American University, and a Doctor of Philosophy in microbiology from Howard University. As a health advocate, Dr. Jackson commits her time and talents to a spectrum of public services that impact her community. She has received several honors and distinctions, including the American University Alumni Recognition Award and the United Negro College Fund's Outstanding Young Alumnus in 2004. She was an inaugural recipient of the Gates Millennium Scholarship and was a 2009 Christine Mirzayan Science and Technology Policy Fellow with the National Academies of Medicine's Roundtable on the Promotion of Health Equity and the Elimination of Health Disparities. Dr. Jackson has displayed commitment throughout her career to utilizing her scientific acumen and leadership skills to improve health and reduce the burden of disease, especially among vulnerable and marginalized groups.

Katherine Johansen Taber (co-chair), Ph.D., is the Vice President of Clinical Product Research & Partnerships at Myriad Genetics. She was formerly the Director of Science Policy at the American Medical Association, with a focus on educating physicians about the clinical implementation of genomics and precision medicine, and on identifying and managing genomics and precision medicine policy issues affecting health care providers. She has held numerous positions on advisory committees and boards of organizations working to improve clinical adoption of genomic technology. Katie earned her PhD in Molecular, Cell, and Developmental Biology at the University of California, Los Angeles, and conducted post-doctoral research at the USDA. She has held teaching appointments at UCLA, California State Polytechnic University, University of Idaho, and Columbia College Chicago.

Vence Bonham, Jr., J.D., received his bachelor of arts from James Madison College at Michigan State University and his juris doctor degree from the Moritz College of Law at the Ohio State University. Mr. Bonham was a fellow in the American Association of Medical Colleges Health Services Research Fellowship Program. Mr. Bonham was a faculty member at Michigan State University in the Colleges of Medicine and Law.
Since 2003, Mr. Bonham has served as an associate investigator in the National Human Genome Research Institute (NHGRI) within the Division of Intramural Research's Social and Behavioral Research Branch. He leads the Health Disparities Genomics Unit, which conducts research that evaluates

approaches to integrating new genomic knowledge and precision medicine into clinical settings without exacerbating inequities in healthcare delivery. His research focuses primarily on the social influences of new genomic knowledge, particularly in communities of color. He studies how genomics influences the use of the constructs of race and ethnicity in biomedical research and clinical care and the role of genomics in health inequities. The Bonham group has expanded to study sickle cell disease, a condition with a significant health disparity impact both in the United States and globally. Mr. Bonham also serves as the senior advisor to the NHGRI director on genomics and health disparities. This role complements Mr. Bonham's research work as it enables him to ask conceptually based research questions grounded in the science of health disparities and genomics. From 2011 until 2015, Mr. Bonham was the project leader and co-curator for the NHGRI/Smithsonian exhibition "Genome: Unlocking Life's Code."

Neil Hanchard M.B.B.S., D.Phil., received his MD (MBBS with Honours) from the University of the West Indies in Kingston, Jamaica, after which he was award the Jamaica Rhodes Scholarship to the University of Oxford, UK. There, he completed a D.Phil. in Human Genetics and Clinical Medicine in the laboratory of Prof. Dominic Kwiatkowski, where he worked on population differentiation, genome variation, and natural selection in the Major Histocompatibility Complex. After returning to Jamaica to study sickle cell disease and severe childhood malnutrition as a clinical research scholar, he moved to the US to do his pediatric residency at the Mayo Clinic in Rochester, Minnesota, before completing a Medical Genetics fellowship at Baylor College of Medicine (BCM) in Houston, Texas. Soon after, he started his own lab as a tenure-track physician scientist in the Department of Molecular and Human genetics at BCM, focusing on the genetics of complex childhood diseases in diverse populations. In addition, Dr Hanchard cared for patients with rare genetic disorders and directed a medium throughput core genetics laboratory, in addition to mentoring and teaching graduate students, medical residents, and medical students. His research has provided insight to the population genetics of the mutation that causes sickle cell disease, identified novel genes in the development of congenital cardiovascular disorders and rare Mendelian disorders, and made inroads to understanding the pathogenesis of diabetic embryopathy, severe childhood malnutrition and transfusion alloimmunization in sickle cell disease. Dr. Hanchard has served in multiple advisory positions for research institutions, the American Society for Human Genetics (ASHG), and genetics journals, and he was the first Early-Career board member of ASHG. He is a fellow of the American College of Medical Genetics and the Society for Pediatric Research. Dr. Hanchard is the current Chair of the Genome Analysis working group of the H3Africa Consortium and an NIH Distinguished Scholar.

Erica Ramos, M.S., C.G.C., is the Vice President of Population Genomics at Genome Medical, a national medical practice with the mission of integrating genomics into everyday health care. She is responsible for developing the strategy, value proposition and overall approach to population-scale health initiatives utilizing genetics and genomics and is passionate about establishing genomics as a resource for life-long care and integrating broad-based screening approaches with indication-based diagnostic services. In her previous role as Director of Clinical & Product Development at Geisinger National Precision Health, she and her team developed and integrated scalable, efficient and innovative clinical programs and products to accelerate the

responsible adoption and integration of genomics into preventive care and population health. Prior to joining Geisinger, Erica was an Associate Director of Market Development for Precision Health & Screening at Illumina and practiced as a clinical genetic counselor for 11 years. Erica is a nationally recognized leader in the genetic counseling community, serving as the 2018 President of the National Society of Genetic Counselors, the leading professional organization for genetic counselors more than 4,000 members strong, and on the *All of Us* Research Program Advisory Panel. She is also an adjunct professor in the Genetic Counseling Department at Augustana University and shares her enthusiasm for genomics, genetic counseling and Wisconsin sports on Twitter at @ERamosSD.

Sharon F. Terry, M.A., is President and CEO of Genetic Alliance, an enterprise engaging individuals, families and communities to transform health. Genetic Alliance works to provide programs, products and tools for ordinary people to take charge of their health and to further biomedical research. As 'just a Mom' with a master's degree in Theology, she cofounded PXE International, a research advocacy organization for the genetic condition pseudoxanthoma elasticum (PXE), in response to the diagnosis of PXE in her two children in 1994. With others, she co-discovered the ABCC6 gene, patented it to ensure ethical stewardship in 2000, and assigned their rights to the foundation. She subsequently developed a diagnostic test and conducts clinical trials. She is the author of 150 peer-reviewed papers, of which 30 are clinical PXE studies. Her story is the topic of her TED Talk and TED Radio Hour.

Catherine A. Wicklund, M.S., C.G.C., is the Director of the Graduate Program in Genetic Counseling at Northwestern University and an Associate Professor in the Department of Obstetrics and Gynecology. She has over 20 years of experience in clinical genetic counseling and has provided prenatal and pediatric genetic services. She served on the Board of Directors of the National Society of Genetic Counselors first as Region V Representative, then as Secretary and was President in 2008. Currently she is a member of the Illinois Department of Public Health's Genetic and Metabolic Diseases Advisory Committee, the Advisory Committee on Hereditable Disorders in Newborns and Children, the American Society of Human Genetics representative on the Scientific Program Committee of the 2016 International Congress of Human Genetics and the NSGC representative on the Institute of Medicine Roundtable on Translating Genomic Based Research for Health. Ms. Wicklund's research interests include issues regarding whole genome/exome sequencing and personalized medicine, psychosocial and counseling issues, and professional issues including workforce and access to and delivery of genetic services. She is a co-investigator on the Electronic Medical Records and Genomics (eMERGE) Network, which aims to bring personalized medicine into broader clinical use. She received her Master of Science degree in Genetic Counseling from the University of Texas-Graduate School of Biomedical Sciences and is a diplomat of the American Board of Genetic Counseling.

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Roundtable on Genomics and Precision Health

Roundtable on Genomics and Precision Health

Improving Diversity of the Clinical Genomics Workforce

SPEAKER GUIDANCE: CONTEXT AND QUESTIONS

The Genomics Roundtable completed a strategic planning process and have started to implement our plans in 2021. One of our working groups, the Equity Group, seeks to foster action related to underrepresentation and inequities in genomic research, the workforce, and access to genomic services by people who need them. As a first step and the goal of this public workshop, the Equity group would like to host a discussion on the actionable next steps for increasing diversity in the clinical genomics workforce.

Session I

Objectives

- To examine the fundamental structural challenges that have resulted in a lack of diversity in the genetics/genomics workforce and explore new opportunities for change.
- To discuss action-oriented efforts of medical and genetics professionals related to workforce diversity and consider how those efforts will attempt to address the structural issues facing the community.

Key Questions for Speakers:

1. As many of you have spent much of your careers trying to improve diversity, equity, and inclusion, what has recently changed (or remains unchanged) that makes this point in time different?
2. What is *one* major change at the *individual* level and one at the *institutional* level that if it could happen, would significantly improve the trajectory of workforce diversity for the better?
3. What different approaches need to be considered for (a) recruiting new staff/students, (b) onboarding new staff/students and then (c) retaining them in the program/workplace?
4. How have workforce policies or programs evolved over the years and what challenges remain? What is needed to overcome those challenges?
5. What forces in the genetics/genomics field have thwarted diversity, equity, and inclusion? What more can be done on the institutional and individual level to advance workforce diversity?
6. What can the Roundtable on Genomics and Precision Health do to help increase the diversity of the genomic workforce?

Session II

Objectives

- To explore the relationship between the lack of diversity in the workforce and patient access to genetic services, understand why workforce diversity matters for patient care, and examine the ways in which professional societies and associations can make a difference in this area.

Key Questions for Speakers:

1. What do you believe is the link between workforce diversity and patient care/patient access to genomic services?
2. How do we translate what we heard about in Session 1 into improved care for patients?
3. What are 1 or 2 obstacles that you've heard about during the workshop that deserve more attention? Are there potential solutions that could start to address these barriers?
4. What have you heard during the workshop that you would suggest others take back to improve diversity, equity, and inclusion at their respective organizations?
5. What didn't we cover during the workshop that needs attention? What other stakeholders need to be part of the conversation?
6. What can the Roundtable on Genomics and Precision Health do to increase the diversity of the genomic workforce?

SESSION I: EXPLORING WORKFORCE DIVERSITY ISSUES IN GENETICS/GENOMICS

Moderator: Jacquelyn Taylor, Helen F. Petit Professor of Nursing, Founder and Executive Director, Center for Research on People of Color, Columbia University School of Nursing

12:10 pm **Overview of Workforce Issues in Genetics/Genomics**

Barbara Harrison
Genetic Counselor
Assistant Professor
Department of Pediatrics
Howard University College of Medicine

Sylvia Mann
Supervisor, Genomics Section
State of Hawaii Department of Health
Director, Western States Regional Genetics Network
Minority Genetic Professionals Network

Omar Abdul-Rahman
Director of Genetic Medicine
Munroe-Meyer Institute
University of Nebraska Medical Center

1:15 pm **Discussion**

1:35pm **Break**

SESSION II: LEARNING FROM THOSE IN THE GENETICS/GENOMICS COMMUNITY

Moderator: Sharon Terry, President and CEO, Genetic Alliance

1:55 pm **Voices From the Community**
Improving diversity and impact on outcomes for patients

Altovise Ewing
Senior Science Leader
Genentech

Damian Archer
Assistant Dean for Multicultural Affairs
Clinical Assistant Professor of Family Medicine
Tufts University School of Medicine
with

Dallas Reed
Division Chief of Genetics
Tufts Children's Hospital
Director of Perinatal Genetics
Tufts Medical Center

LaTasha Lee
Vice President
Clinical & Social Research and Development
National Minority Quality Forum

Catalina Sol
Executive Director
La Clinica del Pueblo

2:50 pm **Panel Discussion**

3:15 pm **Reflections from the Workshop and Final Comments**

LOGISTICAL INFORMATION

The meeting will be held by Zoom videoconference. Briefing materials and a link to join the meeting will be sent to you about two weeks prior to the meeting date. Please provide us with your current short biosketch and any background materials that you would like us to share with the Roundtable members before your talk.

Please join the meeting at least 10 minutes prior to the start of your session. PowerPoint slides are optional, but if you plan to use slides, please email them to **Lydia Teferra (lteferra@nas.edu)** by **Monday, October 4, 2021**. We will look to you to screen share your slides unless you instruct us to do so.

EXPECTED AUDIENCE

In addition to the 35 Roundtable members we expect to participate in this virtual workshop, the meeting is open to the public and we expect hundreds of attendees. Members and the public will likely represent a broad array of stakeholders including academic and industry experts, regulators, clinicians, patients, and patient advocates who will be well-informed about genetics and genomics with varying degrees of experience related to workforce DEI efforts.

Thank you very much for your willingness to share your thoughts, time, and expertise with the Genomics Roundtable!

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Board on Health Sciences Policy
Roundtable on Genomics and Precision Health

Improving Diversity of the Genomics Workforce: A Workshop

October 5, 2021

Speaker Biographies

Omar Abdul-Rahman, M.D., is the current Director of the Department of Genetic Medicine and Friedland Professor at the UNMC Munroe-Meyer Institute. He formerly served as Division Director for Medical Genetics and Vice Chair for Faculty Development in the Department of Pediatrics at the University of Mississippi Medical Center (UMMC). He also was the founding director of UMMC's Center of Genetic Medicine. Dr. Rahman's practice is focused primarily on adult and pediatric patients in a general genetics clinic as well as inpatient consults for pediatrics, prenatal, and adult genetics. He also has participated in the teaching of genetics to the first-year medical school class with a focus on genetic principles, common genetic conditions, and pharmacogenetics.

Damian Archer, M.D., became a member of the Tufts faculty in 2012 as a clinical instructor and is currently the Assistant Dean for Multicultural Affairs and an Assistant Clinical Professor in the Department of Family Medicine, as well as Associate Director of the Tufts Student Service Scholars program. He is also the Chief Medical Officer at North Shore Community Health Center in Salem, MA, and is a board-certified Family Medicine physician. He completed his undergraduate degree at The University of Western Ontario, London, Ontario, Canada with a B.Sc. in Chemistry with Distinction in 2001. He was a successful MBBS (MD) and B. Med. Sci. with Honors candidate at the University of the West Indies, Bahamas Clinical Campus in 2006. He finished his family medicine training at the St. Luke's Family Practice Residency Program at Aurora St. Luke's Hospital in Milwaukee, Wisconsin as Chief Resident of the Family Medicine program in 2011. Dr. Archer sits on the committee on Diversity at the Massachusetts Medical Society and has a passion for developing diverse and inclusive learning and working environments.

Altovise T. Ewing, Ph.D., L.C.G.C., is a clinician-scientist with 10+ years of genetic counseling and health disparities research experience. She earned a Ph.D. in Genetics and Human Genetics with a specialization in Genetic Counseling from Howard University. She completed a cancer health disparities postdoctoral research fellowship at The Johns Hopkins University Bloomberg School of Public Health. Altovise has dedicated her career to ensuring that emerging genetic and genomic resources, services and technologies do not further exacerbate health disparities and inequities. Her unwavering passion for health equity and inclusion has facilitated opportunities for her to engage with various audiences in the genetics

and genomics industry. She also has experience serving as a trusted and committed healthcare liaison to marginalized, medically underserved, and underrepresented communities participating in research. Her scholarship focuses on inclusion of diverse patient populations in cancer genetics research and the development of ethically sound educational strategies to better serve and address the needs of medically underserved populations. Currently, Altovise serves as a Senior Science Lead on the Global Health Equity and Population Science Strategy (HEPS) team at Genentech.

Barbara Harrison, M.S., C.G.C., graduated with a Bachelor's degree in Biology from University of Maryland, College Park and received a Master's degree in Genetic Counseling from University of Pittsburgh. She is certified by the American Board of Genetic Counselors and currently serves on its Board of Directors. She is currently an Assistant Professor at Howard University and teaches graduate students, medical students, and medical residents in various specialties, in the areas of genetics, genetic testing, genetic counseling and ethics. In addition to her academic duties, she provides genetic counseling services at Howard University Hospital for a variety of referral reasons, in areas including prenatal (primary), pediatric, and adult genetics. She is the Assistant Director for Community Outreach and Education for the HU Center for Sickle Cell Disease. She was recently awarded the 2020 NSGC Natalie Weissberger Paul National Achievement Award, the organization's most distinguished honor. In the community, Mrs. Harrison volunteers with the Sickle Cell Association of the National Capital Area, and is an active member of Metropolitan Baptist Church in Largo, MD.

LaTasha Lee, Ph.D., M.P.H., is the current vice president of Clinical & Social Research and Development at the National Minority Quality Forum (NMQF). She is responsible for the oversight and implementation of research projects and programs focused on reducing patient risk and identifying optimal care to reduce health disparities and bring about health equity. She also provides input into the overall strategy for research partnerships and health equity research for NMQF. Prior to joining the NMQF she was the Senior Manager of Partnership Engagement of the Sickle Cell Disease Clinical Trials Network (SCD CTN) at the ASH Research Collaborative. On the global front, she was co-lead on the development of a Newborn Screening and Early Interventions Consortia for SCD in sub-Saharan Africa. A knowledgeable, skilled and energetic scientist and public policy advisor with experience on Capitol Hill, Dr. Lee has worked very closely with Congress and federal agencies to monitor biomedical research and access to care policy related to various diseases impacting communities of color. She earned her Ph.D. in Integrative Biology with a concentration on Neuroscience from Florida Atlantic University, a M.P.H. in epidemiology from The George Washington University (GWU), and a Bachelor's in Biology from Florida A&M University. Dr. Lee is an Adjunct Assistant Professor at GWU School of Medicine and Health Sciences and the recipient of numerous awards including the 2018 National Minority Quality Forum's 40 Under 40 Leaders in Minority Health, Congressional Black Caucus Health Braintrust Staff Leadership Award in recognition of efforts to end health disparities and the Distinguished Alumni Award from Florida Atlantic University.

Sylvia Mann, M.S., C.G.C., is the Project Director for the Western States Regional Genetics Network. She is a certified genetic counselor who has been the Hawaii State Genetics Coordinator since the Genetics Program was started within the Department of Health in 1993. In her position, Ms. Mann has responsibility for assessment, assurance and policy development in

the areas of genetics, newborn screening, birth defects and other related areas such as chronic disease. She has also been the principal investigator on several federally funded projects to assess the genetic service and newborn screening needs of professionals and families; using the needs assessment information to plan activities to address the identified needs; and implement and evaluate the activities. In addition to her state and regional work, Ms. Mann has served on regional and national committees including the Secretary's Advisory Committee on Genetics, Health and Society. Ms. Mann received her Master's of Science degree in human genetics and genetic counseling from Sarah Lawrence College in 1988.

Dallas Reed, M.D., is a double-boarded obstetrician/gynecologist and medical geneticist who has a passion for equity and inclusion, telemedicine, genetics education, and providing sensitive and culturally competent care to women and families during pregnancy and when confronted with uncertainty around a genetic diagnosis. She has clinical expertise with prenatal, pediatric, adult, and cancer genetics, as well as preconception, obstetrics, and gynecologic care. Dr. Reed grew up in Plano, TX, and is a graduate of historically black institution Dillard University in New Orleans, LA, where she received a B.S. in Biology. She joined the Boston University School of Medicine Early Medical School Selection Program (BUSM EMSSP) as a Sophomore and matriculated into the medical school after graduation, where she earned her M.D. degree. She is an Assistant Professor in OB/GYN at Tufts University School of Medicine. She is the Division Chief of Genetics in the Department of Pediatrics at Tufts Children's Hospital; Director of Perinatal Genetics and Attending Physician in the Department of OB/GYN at Tufts Medical Center. Dr. Reed holds several leadership responsibilities, including: Chair of the Tufts Medical Center Physicians Organization's (TMC PO) Telemedicine Steering Committee, an inaugural member of the TMC PO Diversity and Inclusion Committee, and a member of the TMC PO Women in Medicine and Science Committee and Policy and Procedures Committee. At Tufts University School of Medicine (TUSM) she is a member of the Admissions Committee and Sub-committee and inaugural member of the Anti-racism Task Force (charged with creating an anti-racist medical school curriculum).

Catalina Sol, M.P.H., has more than 25 years of public health and direct service provision with underserved communities and Latino immigrants. Prior to her selection as Executive Director in 2018, Ms. Sol served on La Clínica's leadership team in several roles, including HIV Department Director, where she led HIV Prevention and Care programs, and Chief Programs Officer, where she was responsible for the overall strategic direction and integration of programs. She is a current fellow of the Robert Wood Johnson Interdisciplinary Research Leaders program and sits on the Board of Directors of the DC Primary Care Association. Ms. Sol received a Master in Public Health from Johns Hopkins University and a Bachelor's from Georgetown University.

BACKGROUND MATERIALS

CORRESPONDENCE | Genetics inMedicine

An Anti-Racism Toolkit for the Genetics Educator

To the Editor:

I write to you today during a time of unprecedented loss. In the midst of a global pandemic, senseless deaths due to structural racism and police brutality continue. Our collective grief rages as our core values of equity and inclusion are challenged by events we see play out far too frequently, especially in the Black community, and most recently involving George Floyd, Breonna Taylor, Ahmaud Arbery, and far too many others.

At first glance, it may seem like these events are separate from our professional identities as geneticists, but Dr. Gregg correctly recognizes the fact that structural racism has played a role in the practice of genomic medicine and that there are steps we can take as a profession to address these disparities.[1] As our nation struggles to find our way out of darkness and toward a more just society, we scientists, clinicians, and educators must seek ways to turn anguish into action. We must unite to condemn racism, but that response alone is inadequate. It is also our responsibility to empower our community to acknowledge privilege for those who benefit from it and to help disseminate tools to dismantle structural racism. Toward that end, in my role with the Association of Professors of Human and Medical Genetics (https://www.aphmg.org/), an organization that brings together medical genetics educators and program directors, I am particularly interested in tools that can help us have these conversations in our training programs. Geneticists are in the unique position of being able to underscore our common humanity with evidence from our collective genomic history.[2] It is up to us to create inclusive training environments where these topics are explored and used to shine a light on systems of care in our country.

It is important to note that scientific teaching about human genetic variation designed to challenge students' pre-existing views on the biological relevance of race has been demonstrated to significantly decrease cognitive measures of prejudice.[3] In other words, how we teach can address student misconceptions about race and provide a more accurate framework for them to view medical knowledge that is frequently racialized. This framework can be introduced using educational modules that provide trainees with foundational understanding of human genetic variation across and within populations.[4] It is equally important to provide historical context for how these systems originally came to be, to ask how we got here, in order to prevent the resurgence of race pseudoscience with modern genomic information.[5] This context sets the stage for detailed examination of health-care disparities resulting from inequitable representation in genomic databases, genetic testing tailored for limited ancestral groups,[6,7] and the use of race as a proxy for biological risk factors.[8] Taken together, these lessons can highlight the significant flaws with the use of race in the practice of genomic medicine and the structural inequities caused by racism itself, not genetics.[9]

Current events have underscored the horrifying consequences of marginalizing members of our society, and as pointed out by Dr. Gregg, in order to derive any meaning from the pain of this moment in history, we must not allow this awareness to fade into the background of our daily lives.[1] Rather, we must commit to this call to action, and for those of us who educate the next generation of providers, we must carefully consider how our classrooms and clinics can promote the ideals of inclusion in order to work toward eliminating health-care disparities. It is my hope that the educational materials and lesson plans shared here will help you start on this journey. Please join me in committing to healing and learning together so that we may work towards a more equitable future.

DISCLOSURE

S.D. declares no conflicts of interest.

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SPECIAL ISSUE

National Society of Genetic Counselors WILEY

Conscripted curriculum: The experiences of minority genetic counseling students

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Abstract

While the lack of racial and ethnic diversity in the genetic counseling profession has been discussed for decades, little attention has been paid to the training experiences of under-represented minorities. Under-represented minority graduate students in other disciplines have been reported to experience microaggressions and feelings of isolation during training, and they are often informally enlisted to educate classmates about issues related to race. In 2019, sociologist Lauren Olsen coined the term *conscripted curriculum* to describe the utilization of minority medical students to elucidate issues of race or ethnicity for their classmates. The conscripted curriculum arises when these topics are taught in a small-group discussion format that relies on students sharing their individual experiences to educate their classmates. In classrooms with limited diversity, the expectation to contribute falls disproportionately on students from non-majority groups. In this qualitative study, we conducted videoconference focus groups with 32 recent graduates of genetic counseling training programs who identified as racial or ethnic minorities. We present the results of two thematic categories that emerged from that study: the participants' perspectives on the cultural competency curriculum in their training programs and the participants' feelings of being pressed into service as spokespeople for their cultural groups. Participants described the cultural competency training as occurring primarily in a small-group discussion format in which students were expected to share their personal experiences. During these discussions, minority students, especially those in less-diverse class cohorts, felt obliged to contribute their perspectives in order to educate non-minority classmates about issues of race and ethnicity, leading to feelings of frustration and exhaustion. The results reflect a conscripted curriculum as described by Olsen (2019). *Journal of Health and Social Behavior*, 60(1), 55–68, in which minority students bear the burden of educating their classmates about the social basis of race. Genetic counseling training programs should critically examine their cultural competency curriculum to create a more equitable training environment.

KEYWORDS

conscripted curriculum, cultural competence, diversity, genetic counselors, graduate school, minority

1 | INTRODUCTION

1.1 | Diversity of the Genetic Counseling Profession

According to the National Society of Genetic Counselors (NSGC) 2019 Professional Status Survey (PSS), genetic counselors in the United States and Canada are overwhelmingly White (90%), with 5% identifying as Asian, 3% as Asian Indian, 2% as Hispanic/Latino(a), 1% as Black/African American, <1% as Native American, and 1% as Other (National Society of Genetic Counselors, 2019). These percentages have changed little over a period of decades (Mittman & Downs, 2008), despite efforts dating back to at least 1991 to recruit and retain under-represented minorities. This raises questions about the culture of genetic counseling education and the experiences of under-represented minority students as they navigate the admissions process, graduate coursework, and clinical experiences.

In a study conducted more than a decade ago, Schoonveld, Veach, and LeRoy (2007) found that genetic counselors who identify as racial or ethnic minorities report a variety of problematic experiences related to their minority status: Some felt their culture was ignored completely; others felt their culture was treated as their sole identifying characteristic; and some felt pressured to serve as 'diversity experts' and act as a bridge between their community and the field of genetic counseling. To our knowledge, no research has been published since the 2007 study about the training experiences of genetic counseling students who identify as racial or ethnic minorities.

A growing body of research focuses on the experiences of minority graduate students in other academic and clinical fields. Studies across a variety of contexts have shown that minority students experience microaggressions (Smith, Allen, & Danley, 2007; Torres, Driscoll, & Burrow, 2010), feel lower relative levels of belonging in the field than their counterparts from the majority race or ethnicity (Clark, Mercer, Zeigler-Hill, & Dufrene, 2012), and experience increased feelings of isolation (Brunsma, Embrick, & Shin, 2017; Gay, 2004). At the same time, under-represented minority students sometimes feel themselves enlisted to educate classmates about issues related to race. Morrison (2010) interviewed 21 students of color at a predominantly White university and found that ignorance among their classmates 'leaves students of color with two options: either assume the responsibility for educating their peers or learn to live with the frustration of dealing with ignorant comments' (Morrison, 2010, p. 1,004). While some of these respondents said they enjoyed teaching White peers about diversity and culture, others expressed frustration at being thrust into the role. Similarly, Walls and Hall (2018) found Black/African American undergraduates at a predominantly White college felt pressured to provide the 'Black perspective' to classmates when issues of race were raised. Regarding religious identity, Muslim students face the challenge of establishing their individuality within a religion that spans multiple continents and cultures, while simultaneously feeling compelled to appear as a homogeneous group (Wang, Raja, & Azhar, 2019).

Conversations about race that arise in the classroom may be challenging for both students and instructors. Sue (2013) investigated these 'difficult dialogues', interactions between members of different racial or ethnic groups, and found that such dialogues reveal major differences in worldviews and can arouse intense emotions that differ by race: dread and anxiety for White students, and anger and frustration for students of color. Studies have shown that students of color recognize the potential for intense discomfort and make conscious decisions before choosing to contribute to a conversation; for example, they may weigh the safety of the environment and their ability to maintain their composure against their responsibility to speak up (Sue, 2013; Walls & Hall, 2018). Instructors inexperienced in facilitating difficult dialogues about race and racism may fear the potential of these discussions to trigger intense emotions and react by diverting conversations to topics they perceive as safer and less controversial (such as social class), urging students to calm down, or tabling the discussion (Sue, 2013; Sue, Torino, Capodilupo, Rivera, & Lin, 2009).

1.2 | Conscripted curriculum

Sociologist Lauren Olsen (2019) recently coined the term *conscripted curriculum* to describe the utilization of minority medical students to elucidate issues of race or ethnicity for their classmates. Through interviews with 60 educators and 30 students at United States medical schools, she found that topics related to race and social inequalities were most often covered in a small-group format because of the perceived benefit of student participation. For example, a class might be presented with a hypothetical patient scenario to discuss in groups of 8 to 12 students, with the 'expectation that students will share their personal experiences with race, and that in sharing these experiences, other students will learn about the social nature of race' (Olsen, 2019, p. 62). Olsen (2019) identified two major disadvantages to this format. First, it positions descriptions of discrimination and mistreatment as matters of students' individual experiences rather than 'systemically collected facts about the historical and contemporary effects of race and racism' (Olsen, 2019, p. 66), thereby diminishing the utility of these examples in exposing structural disparities. Second, in educational settings with limited diversity, this format places a disproportionate burden on the few racial or ethnic minorities to teach their classmates about the social nature of race. These students become the 'workhorses' of the discussion, because they are either directly prompted to participate or feel compelled to do so as the only person of their minority background. This kind of 'emotionally taxing and unrewarded labor' (Olsen, 2019, p. 59) is expected of students of color but not of their White classmates; it reproduces the status of people of color as workers relative to their White classmates, and it may lead to feelings such as disillusionment, frustration, and exhaustion.

Olsen concludes that this type of interracial contact may not be beneficial for any of the students; it fails to challenge the implicit biases of White students or convince them of the social basis of race, and it 'perpetuates racial inequality by placing an

additional burden on students of color' (Olsen, 2019, p. 62). Finally, she suggests that the concept of the conscripted curriculum can be extended beyond identities centered on racial or ethnic characteristics to describe the experiences of any student who is placed in the position of having to educate classmates about some aspect of their social identity.

1.3 | Cultural competency

Issues related to race, ethnicity, and culture are often addressed within curricula designed to foster 'cultural competency'. However, there is heterogeneity across health professions in the definition of cultural competency and also in the range of approaches to teaching it. McGibbon and Etowa (2009) surveyed the healthcare literature and found definitions that included acknowledging and affirming cultural differences; understanding how race, culture, and ethnicity contribute to uniqueness; recognizing differences among and within cultural groups; respect for difference and an eagerness to learn; addressing healthcare disparities or vulnerabilities due to minority status; and conducting cultural self-assessment. Other writers have argued that teaching for cultural competency should include developing a social justice orientation by fostering student reflection on the differences in power and privilege that impact the therapeutic relationship (Kumagai & Lypson, 2009), teaching students about the political and economic conditions that produce health inequities (Metzl, Petty, & Olowojoba, 2018), and focusing on the recognition of unconscious bias and stereotypes (Paul, Ewen, & Jones, 2014).

One of the competencies required of graduating genetic counseling students is to demonstrate that they can 'apply genetic counseling skills in a culturally responsive and respectful manner to all clients' (Accreditation Council for Genetic Counseling, 2019a, p. 5). The Standards of Accreditation require that training programs teach 'multicultural sensitivity and competency' (Accreditation Council for Genetic Counseling, 2019b, p. 20), and the certification examination includes questions designed to evaluate whether candidates can 'assess client and/or family cultural/religious beliefs, traditions, and values' and 'utilize cross-cultural genetic counseling techniques' (American Board of Genetic Counseling, Inc., 2018, pp. 5, 6). Weil (2001) recommended that this training include three components: information about the cultures that students may encounter in clinic; self-reflection on students' own culture and beliefs; and an awareness of institutional and social barriers to accessing health care.

1.4 | Study purpose

The overall purpose of this qualitative study was to examine the genetic counseling training experience from the perspective of students who identify as racial or ethnic minorities. Of note, participants in this study are described as 'individuals who identify as racial or ethnic minorities', following the terminology used by the Minority Genetics Professionals Network (MGPN). Within this article, the term 'minority' refers specifically to those individuals who identify as racial or ethnic minorities.

2 | METHODS

IRB approval was obtained from Simmons University, granted to the first author in 2019 as part of a larger dissertation research project. This qualitative study utilized the principles of constructivist grounded theory (Charmaz, 2014), an approach that acknowledges the inherently subjective nature of grounded theory research and is so-named because the data are seen as 'constructed' by the researcher and the participants, influenced by participants' experiences, selected theoretical lenses, and the researcher's interpretation (Creswell, 2007). In contrast to other grounded theory methodologies, constructivist grounded theory acknowledges the influence of existing literature in identifying 'points of departure' that inform the interview questions and data analysis (Charmaz, 2014). In this study, such points of departure included concepts in existing literature from other professions, such as academia and mental health counseling, regarding the experiences of individuals who identify as racial or ethnic minorities.

2.1 | Participants

Eligible participants for this study included individuals who graduated from genetic counseling programs between 2017 and 2019 and who self-identified as a racial or ethnic minority. We selected this time frame to ensure an adequately large participant pool while also enhancing recall of the clinical training experience. Exclusion criteria included having trained or completed a clinical internship with the first author.

2.2 | Procedures

Recruitment of participants involved targeted sampling and snowball sampling via email blasts sent by the NSGC and the MGPN. The recruitment email included a link to a Qualtrics.com questionnaire. Participants who clicked on the link were directed to a page in which they could consent to: (a) participate in the study; (b) be audio- and video-recorded; and (c) maintain the confidentiality of other study participants. Those who consented to all three conditions were then routed to a demographics questionnaire. As part of the questionnaire, participants were asked to describe their racial or ethnic identity in their own words, and then to select from a drop-down menu of racial or ethnic categories those with which they felt the most affinity. Categories included in the drop-down menu were drawn from the classification system used by NSGC on the PSS (i.e., American Indian or Alaskan Native, Asian, Asian Indian, Black or African American, Hispanic or Latino(a), Native

Hawaiian or Pacific Islander, White or Caucasian, Other) (National Society of Genetic Counselors, 2019). Participants were also asked to select a pseudonym.

The first author contacted each participant to schedule them for a focus group. Data were collected via focus groups rather than individual interviews for two primary reasons. First, it has been found that focus groups have the potential to generate more novel themes than do one-on-one interviews, as ideas arise through discussion among the participants (Barbour & Kitzinger, 1999; De Jong & Schellens, 1998; Kaplowitz, 2000; Morgan, 2018). This is a particularly important benefit in situations where relatively little is previously known about the research topic. Second, focus groups shift the balance of power from the researcher to the participants (Farquhar & Das, 1999; Kook, Harel-Shalev, & Yuval, 2019; Wilkinson, 1999). Given that the first author was an older White woman who was interviewing recent graduates about their experiences as racial and ethnic minorities, we wanted to maximize the comfort and empowerment of the participants during the discussion. Focus groups were conducted via Zoom.us videoconferencing to enable recruitment of participants throughout the United States (Matthews, Baird, & Duchesne, 2018; Rupert, Poehlman, Hayes, Ray, & Moultrie, 2017). Each group was capped at four participants in order to minimize any potential impact from slow internet speeds and to maximize opportunities for each participant to speak (Abrams, Wang, Song, & Galindo-Gonzalez, 2015; Rosenthal, 2016; Stewart & Shamdasani, 2017).

Between June and October of 2019, the first author facilitated 13 videoconference focus groups using Zoom.us. Each focus group included two or three participants. Care was taken so that participants would not be placed in groups with others from their training programs. When possible, participants were grouped with others who had similar claimed identity affiliations in order to foster 'common ground', the sense that other participants would understand what they were talking about without elaborate explanations (Morgan, 2018). Focus groups lasted between 77 and 115 min (median: 89 min) each, and were audio- and video-recorded.

2.3 | Instrumentation

We developed a semi-structured focus group guide (Table 1) based on a review of extant literature pertaining to the experiences of genetic counseling students, mental health counseling students, and graduate students in general. To maximize face and content validity, multiple rounds of feedback regarding the demographic questionnaire and focus group guide were obtained from nine genetic counselors who identify as racial or ethnic minorities but were not eligible to participate in the study due to graduation date or training location. We piloted both telephone and videoconferencing formats with groups of up to three participants. Questions and prompts were revised based on interviewee input following each iteration; some questions were added or removed, and others were reworded to improve clarity. The final guide included questions about the classroom and clinical environments in which participants trained, the ways in which their racial or ethnic identity positively or negatively impacted the experience, relationships with classmates and faculty, sources of psychological support, and participants' sense of belonging in the genetic counseling profession.

TABLE 1 Focus group guide

Introductions: Preferred name, racial or ethnic identity, languages spoken, description of training program (including racial and ethnic composition of the cohort and faculty)
How, if at all, do you feel that your experience overall was different than that of your White classmates?
Thinking back to experiences in graduate school and in clinic, can you recall a specific instance in which you felt like your race or ethnicity positively or negatively impacted your training?
In preparation for your clinical training, how, if at all, did your graduate program or supervisor discuss how your race or ethnicity might impact the experience?
With the goal of improving the training experiences for students who identify as racial or ethnic minorities, what recommendations, if any, would you make to graduate programs or supervisors?
How, if at all, did you feel like your racial or ethnic identity impacted your sense of being a genetic counselor?
How, if at all, do you think that your experiences impacted your sense of belonging in the genetic counseling profession?

Recordings of each focus group were downloaded to the first author's encrypted and password-protected laptop and sent for transcription by a professional transcriptionist approved by the university IRB. Resulting transcripts were reviewed for accuracy, and participant names were altered to reflect their preferred pseudonyms.

2.4 | Data analysis

The data were placed into NVivo, a software program for qualitative data analysis. The first author coded the transcripts as they were received so that themes emerging from each focus group informed the groups that followed in a constant-comparative approach (Charmaz, 2005, 2014; Creswell, 2007; Hood, 2007; Massey, 2011). In the initial coding phase, codes were assigned to words, phrases, and sentences based on a priori (from the literature and the interview guide) as well as emergent themes (Corbin & Strauss, 2008). As analysis proceeded, codes were merged or discarded, eventually coalescing into categories. To support validity and reduce interpretive bias, selected portions of the focus group transcripts, comprising approximately 25% of the data, were independently coded by members of the first author's dissertation committee who identified as racial or ethnic minorities; the first author and committee members examined coding discrepancies and discussed emergent themes. Quotes selected for the present article were taken directly from participants and modified only by removing filler words (such as 'like' or 'kind of') for brevity.

3 | RESULTS

3.1 | Participant characteristics

Forty individuals accessed the Qualtrics form; four did not complete the consent form, four were excluded because they did not meet the criteria for the study, and the remaining 32 were eligible to participate in the study. The 32 participants included 28 females and four males representing a total of 14 training programs, with between one and six participants from each program. Participants identified themselves as having 'the most in common' with the following NSGC categories: Asian (*n* = 12), Asian Indian (*n* = 11), Hispanic or Latino(a) (*n* = 7), White or Caucasian (*n* = 7), Black or African American (*n* = 4), and Other (*n* = 2). Participants could select more than one category; those who selected 'White or Caucasian' were all multiracial. Notably, when asked to describe their race or ethnicity, participants described themselves using a range of affinity terms that did not align with the categories used by NSGC, including: African American/Black, Asian, American Chinese, Biracial, Caribbean, Chinese, Desi, Filipino, First-generation, Guyanese-American, Hispanic, Indian, Indian-American, Iraqi, Latina, Mexican, Mixed-race, Muslim, Native American, Nepali Brahmin, Pakistani, Pakistani-American, South Asian, Southeast Asian, West Indian, and 1.5 generation. Most participants graduated in 2018 (*n* = 14) or 2019 (*n* = 14). Twelve participants were under the age of 25, 19 were between the ages of 26 and 30, and one was over the age of 30.

3.2 | Overview of categories and themes

The data for this article were drawn from a larger research project and represent themes that fell within two of that project's eight categories. The themes were derived from codes and were grouped within the categories of *Cultural Competency Training* and *Speaking Up* (Table 2). The category of *Cultural Competency Training* includes statements made by participants regarding the teaching or learning of cultural competency, multicultural counseling, cultural sensitivity, cultural humility, or disparities in access to health care. It encompasses three themes, *Cultural competency scope and curriculum*, *Healthcare disparities*, and *Instructors of cultural competency*. The category of *Speaking Up* includes statements made by participants about sharing their culturally informed perspectives or experiences with members of their training program. It encompasses four themes, *Role in classroom content*, *Being the spokesperson*, *Reactions to speaking up*, and *Tempering comments*.

3.3 | Cultural competency training

3.3.1 | Cultural competency scope and curriculum

Participants indicated that cultural competency is taught in a variety of ways across genetic counseling programs and courses. Most commonly, they reported that cultural competency was presented through a combination of lectures or readings and discussions arising in response to topics in psychosocial classes, role plays, or case presentations. Some recalled lectures and readings about specific non-majority groups, such as Muslims or Hispanics, and others recalled broader topics such as 'multicultural counseling' or grief across cultures. Participants also described instruction that was purported to address knowledge of culture-specific practices, such as being taught to expect that men from the Middle East may speak for their wives, or that death is not discussed in Japanese culture. Participants in three focus groups described this type of content as a list of 'stereotypes' and believed it did not adequately capture the nuances present within cultural groups. Others described the information presented about their own cultures as simplistic or incorrect. Some participants recalled activities designed to encourage students to reflect on and identify their own internal biases.

Participants generally did not perceive that cultural competency training was regarded as a priority by their programs. Rather, they characterized it as a 'check off their checklist', as one put it, or 'not at the forefront of the programs' design', when it 'should have been incorporated throughout every class' and 'be given, in its essence, the right and the space that it deserves'.

3.3.2 | Healthcare disparities

While many participants recalled at least occasional discussions about disparities in healthcare access within their training programs, one Black/African American participant articulated her frustration that her program's coverage of this topic fell short: 'Cultural diversity is important, but understanding that cultural disparity exists is more what you need to hit home. Recognizing there are doctors that still think African Americans need less pain medication… [Genetic counselors] need to understand so that they're not making the same choices'. None of the 32 participants described a curriculum that addressed systemic racism, structural patterns of inequality in healthcare access, or legacies of historic discrimination in depth.

3.3.3 | Instructors of cultural competency

Participants reported that their training programs drew on a number of sources for instructors of cultural competency, including program leadership, practicing genetic counselors in the community, university resources such as diversity offices, and the students themselves, but that the dominant mode of content delivery involved a White person presenting information about 'others'. Participants commented on how this pattern at times impacted their perception of the content. When the instructors were White, participants reported a feeling of general unease, worrying that the information might not be reliable or might reflect inherited stereotypes. They found themselves questioning the authority of the instructors and of the content: 'Where did they get that information?' one

TABLE 2 Categories and themes that arose from focus group discussions with 32 recent graduates of genetic counseling programs who identify as racial or ethnic minorities

Cultural competency training		
Theme	**Definition**	**Examples**
Cultural competency scope and curriculum	The extent or nature of cultural competency training	'We had a couple classes on cultural competency, but it more came up in our case reviews when people would present cases'. 'They give you a list of stereotypes, and they tell you that this is how people who are from a certain culture may behave. And then what people assume is that this is how a person from a certain ethnic background will always behave, they have to fulfill this list of things that you've learned in your books. And that's not true'.
Healthcare disparities	Curriculum addressing healthcare disparities or lack of access to health care	'We'd bring in socioeconomic status and other factors without needing the prompting'. 'What health network are you in, and do your primary care physicians even know that there are genetic professionals in the area that they can refer to? Do they have any idea how to approach genetics-related health issues?'
Instructors of cultural competency	Who is teaching the cultural competency curriculum	'There was quite a few units that were focused on diversity, inclusion, cultural competency. And we invited mostly speakers from outside to come talk about these lectures'. 'Whatever the cultural difference was, we would pick different topics and present in class to each other. While, great, one of us becomes an expert on that topic, I wish there was more of a somewhat kind of forced event, sort of speak'.
Speaking up		
Theme	**Definition**	**Examples**
Role in classroom content	How participant's felt that their perspectives or experiences influenced classroom discussion	'The conversation was more enriched by us bringing our own experiences'. 'There's a billion people in the world that practice Islam, so to kind of turn to me and be, "So, does that sound about right? Is that how you would deal with that patient?" It felt a little pressurized'.
Being the spokesperson	Participants' perceptions about expectations that they share their experiences	'They would expect or appreciate anybody's point of view. But of course, the views of minorities, in a lot of cases, are very enriching. And I think that they were hoping that we would. And we always did'. 'That felt maybe not so nice. Because sometimes, you don't have an opinion, and that's okay because I didn't see my other classmates being singled out, or being called on to have an opinion or have a voice'.
Reactions to speaking up	How participants or members of their training program reacted to them sharing their perspectives and experiences	'It's burdensome to have to feel like you're the spokesperson for anything around anything that touches on culture'. 'You can tell that some people are just getting tired of every single time you open your mouth, it's like 'Oh, she's going to probably talk about diversity or something along those lines'.
Tempering comments	Tempering their statements to reflect that they are speaking only for themselves, not their entire minority group	'I would never be able to say whatever they say in the way that they say it. It would be like, qualifier one, two, three, four, and at the very end, you have to say again, that's really just my opinion. It does not represent everybody'. 'I always have to kind of preface myself that this is just my experience'.

respondent wondered; 'Is it personal experience? Is it actually going out and surveying the community?' Participants remarked that, 'It's just a bunch of people not a part of this culture, who've never experienced this culture, talking about this culture', and, 'Every time we were talking about a minority, it was a White person talking about the minority'. Other participants recalled that individuals from the community were invited to teach about their own cultures. However, one participant recalled that, even when she and the instructor were members of the same broad cultural group, 'I often felt that she was resorting to a lot of stereotypes, and I felt myself having to dispel a few things, and that was a little disappointing … come on, you're in our group'.

At times, comments and content by guest instructors negatively impacted minority students. One participant who wore a *hijab*, a head covering worn in public by some Muslim women, was infuriated by an instructor who 'joked' during her presentation that she (the instructor) would be stoned if she lived in the Middle East because she was so outspoken. The participant explained why she was so angry: 'Some of the strongest women I know have been from there… You see these really close-minded comments that are made … and the fact that she felt like she could say that so comfortably when she could see someone in the front row wearing [a *hijab*]'. Another participant recalled an exercise that was intended to draw students' attention to their privilege, but had the opposite effect of increasing her sense of isolation from her peers: The instructor showed a YouTube video of a line of children running in a race, with their starting points dictated by factors such as race and socioeconomic status; features reflective of minority identity led to a disadvantageous starting point in the race. The participant explained that she did not speak up during the discussion because, 'It really triggered me… Everyone in class, we're talking about how, "Oh, we feel bad for these people." … I'm not going to contribute to this because I actually would have never finished the race, because I would have been way back there'.

Participants also reported that minority students were placed into positions of being asked to teach their classmates as a representative of a non-majority cultural group. Some participants recalled enjoying these opportunities, while others felt obliged to participate in order to educate their peers. One participant described her program's attempt to 'leverage [the] diversity' of their students by inviting those 'who had a cultural background … that you feel warrants your classmates' understanding or will be helpful for them in the future' to share that information in a short presentation; the participant recalled classmates teaching about Black/African American, Indian, and Persian cultures. Another participant was asked to give a lecture about being Latina, and about how her customs and culture impact her interactions with others. As the only minority in her cohort, she declined to present this information; she already felt like she did not fit in with her classmates and did not want to call further attention to her differences. In both of these situations, representatives of minority cultures were positioned as having something outside the norm that needed to be taught, while students from the majority culture were positioned as the neutral baseline to which knowledge had to be added. Two participants reported being so dissatisfied with how cultural competency was taught in their programs that they developed multi-hour workshops for their classmates to address what they felt to be shortcomings.

3.4 | Speaking up

3.4.1 | Role in classroom content

Participants referenced the diversity of the cohort as the primary factor that impacted the quality of classroom discussion. Respondents who trained in diverse cohorts described vibrant discussions as classmates from a variety of backgrounds shared how their experiences were similar to or different from the cultures they were learning about. One participant attributed the success of her program's cultural competency education to the diversity of her cohort, rather than to the quality of the curriculum: 'I think the cultural competency education, whether it was intended or not, just came from having people of diverse backgrounds… It was almost incorporated into every discussion, but not as a lesson'. Another participant remarked that, 'The quality of the conversation is only going to be as good as the people who are part of the conversation'. Others reported that their programs fostered dynamic discussion by inviting and expecting all students to share their cultural perspective, not just those who were visible minorities.

Participants in this study described feeling that their instructors expected minority students to contribute to the discussion from their cultural perspectives in a way that was not expected of their White classmates. For example, one participant recalled that, when topics of multiculturalism would arise, 'The eyes always go toward me and the other students of color in the classroom'. Another mused that, 'I don't think I've ever had one of my White classmates reflect on their culture and how it relates to anything'. A third recalled her frustration that, 'The one time we talked about culture … [My classmates] were all saying, "Well, I'm White, so I guess I don't have anything to talk about culture." … I want you to talk about that. Just because you're White does not mean that you don't have a cultural bias or cultural background'.

3.4.2 | Being the spokesperson, reactions to speaking up

Participants expressed mixed reactions to being expected to share their perspectives. Some participants enjoyed the opportunity to educate their classmates and felt their perspectives were valued by both classmates and instructors. Several reported feeling that, while their contributions were expected, they were also much appreciated. Others reported that they were proud to add diversity to a profession in which it was lacking. 'I needed to be there', one said, 'because if it's not a diverse profession, who's going to speak for everyone?' Being in a more diverse cohort took the pressure off individual students during discussions; because she had minority classmates, one of the students observed, she did not feel that she was made to speak for 'all brown people'. Another was relieved that she did not feel like she was constantly being called to 'serve… as the spokesperson'. A third noted that being in a diverse classroom prevented the feeling of being some kind of 'exotic bird'.

Other participants reported less positive experiences. Some said that they resented being expected to contribute when their White classmates were not, and others felt like their perspectives were not acknowledged. One participant who had first-hand knowledge of communal cultures recalled challenging an instructor's portrayal of the topic; however, she felt her contribution was 'glossed over',

and subsequently hesitated to contribute her perspective. Others, including biracial participants, similarly reported instances in which they felt that their cultural perspective was not valued. In addition, participants reported that sharing their perspective became 'exhausting'. In the words of one: 'I was tired of being the spokesperson … for [my] community—and by my community, I don't just mean Indians, I also mean internationals, I also mean brown people, I also mean racial minorities, biracial people. Having to speak for all of these people got tiring'.

Participants who identified as Muslim felt particular pressure as spokespeople for a religion that spans multiple countries and cultures. They reported feeling torn between, on one hand, needing to speak up to educate their classmates, and, on the other hand, being emotionally exhausted by these discussions. One noted that her classmates expected her to comment on any topic that arose related to Islam, despite there being 'a billion people in the world that practice Islam'. At the same time, failing to speak up also took a toll on her: 'It would sit with me… I don't want my classmates to go out into the workforce [with a misconception]'. Another Muslim participant recalled a presentation that described female genital mutilation as being a practice associated with Islam; 'I remember feeling really, really pressured … If I stay silent, is that saying that, oh yeah, this is a thing we do in our religion? … Is this conversation really happening, where we're painting this broad brush of Muslim people being for this horrific thing?'

Black/African American participants felt that they were expected to speak to the 'Black experience'. One recalled the pressure she felt as the lone Black/African American student in her cohort when her well-meaning classmates wanted to discuss political events, noting that she felt obliged to speak 'on behalf of … my own people, and what they're going through'. While her classmates were grateful for her perspective, she felt compelled to share her thoughts with them because of their lack of understanding. Black/African American participants were also cognizant of the healthcare disparities that disproportionately impact their community, and felt responsible for reminding classmates and faculty of 'the issues of access, and the history of discrimination in the healthcare system… As far as having medical mistrust, where that comes from'.

Some participants reported that they had classmates who failed to recognize how race or ethnicity impacted interactions with patients, and this was a source of great frustration for them. One reported classmates' claims of being 'colorblind' in how they treat patients and felt the responsibility had been placed on her shoulders to demonstrate the logical flaws inherent in this line of thinking. 'That's not the right thing to say', she had to explain, 'because depending on someone's background, you might have to change the way you would treat that patient… So, in those cases, I felt like it was on me to educate them. Those are the times where I felt like it was a burden on me'. Another participant, who generally kept quiet during discussions, retorted to a classmate who voiced her wish that patients disclose their undocumented status to her, 'Not everyone would want to disclose that to you because you're White'. However, she quickly regretted her comment: 'Then I stopped because I was like, I need to hold myself back'.

3.4.3 | Tempering comments

Many participants reported tempering their comments in terms of content, timing, or quantity in order to avoid 'annoying' their classmates. One said that she 'had to pick and choose' when to speak up, because she did not want to be perceived as 'the preachy Black girl'. Another, who was the only minority in her cohort, avoided participating in diversity conversations because she did not want to be 'labeled'. Others felt a need to carefully qualify that their statements were based on their own experiences and did not necessarily reflect the views of other individuals from the same culture. One participant explained that, when a White classmate shared a perspective, it was 'the default, so they're just having a thought', whereas contributions from minorities were perceived as representing a specific cultural perspective.

4 | DISCUSSION

This qualitative focus group study examined the experiences of minority genetic counseling students during their graduate school training. This article focuses specifically on themes that emerged regarding the 32 participants' perceptions of the cultural competency curriculum and their role within this curriculum. By considering first the format of cultural competency training for genetic counseling students, and then the consequences for minority students in this field, we demonstrate that the conscripted curriculum described by Olsen (2019) in medical schools is also present in genetic counseling training programs.

The format of cultural competency instruction in genetic counseling programs is similar to that described by Olsen. In the medical school classrooms she studied, topics related to race and social inequality were most commonly presented as a component of hypothetical case scenarios and discussed in small groups of 8 to 12 students. The purpose of this format was to encourage participation so that students could learn about the social nature of race from each other. The participants in this study described being taught about cultural competency through an array of approaches; most commonly, some content was presented in lectures or readings, but much was taught in a discussion-based format. Similar to the classes described by Olsen, discussions were generated in response to readings or case presentations. In addition, the discussion groups are similar in size to those described by Olsen: According to the Genetic Counseling Admissions Match, 468 students were matched to 48 programs in 2019, for an average cohort size of 9.75 students (https://natmatch.com/gcadmissions/stats/2019stats.pdf, accessed 2/5/2020). Finally, reflecting the lack of diversity in the genetic counseling profession, most participants in this study were the 'only one' of their particular racial or ethnic identity in their cohort.

Given that the format of the cultural competency instruction in genetic counseling is similar to that described in medical schools, it is not surprising that many of the same negative consequences were identified in this study. Participants described being disproportionately responsible for contributing their perspectives in comparison

to their White classmates. Within classroom discussions, many participants felt compelled to speak to answer questions from classmates, correct faulty information, provide a 'different' perspective from some purported non-ethnic baseline, or draw attention to healthcare disparities when faculty did not do so. Other participants perceived that their instructors or classmates expected them to speak up merely on the grounds of having minority status, as if that alone indicated that they had a unique perspective. In some cases, programs went so far as to ask the students to create a lecture to educate their classmates about their culture.

While some participants enjoyed sharing their viewpoints, others were reluctant to do so. Some reported being wary of being 'labeled' by their racial or ethnic identity, some were concerned about annoying their classmates, and others described themselves as tired of the ongoing requirement to 'represent' and 'speak for' a group of people beyond just themselves. In cohorts with more diversity, this burden was significantly lessened, by all accounts, because it was distributed among more individuals.

The experiences of participants varied by minority identity. For example, those who identified as Muslim felt particular pressure as spokespeople for a religion that spans multiple countries and cultures. This mirrors the findings of Wang et al. (2019), who found that Muslim Americans struggle to balance their desire for individuality within the group, while still presenting a united front. Black/African American participants felt responsible for educating their classmates about healthcare disparities that impact their communities. Both of these groups are extremely under-represented in the genetic counseling profession, decreasing the likelihood that they will have classmates who share their minority identity.

Participants navigated with varying degrees of ease a number of competing priorities: the pressure to correct faulty information, the frustration and exhaustion of being cast as a spokesperson for a group, and the desire not to ruffle the feathers of classmates or instructors. While some participants enjoyed sharing their perspectives, others described the experience as 'tiring', 'exhausting', and 'isolating'—the 'emotionally taxing and unrewarded labor' (Olsen, 2019, p. 59) of the conscripted curriculum.

Participants in this study described instructors who were poorly prepared to facilitate discussions about race and social inequality. Some instructors perpetuated stereotypes, such as the speaker who referenced Muslim cultures stoning outspoken women, and others did not speak up to dispel them, as in the instance when female genital mutilation was described as a practice common in Islamic countries. One participant reported that she had to remind her classmates that being White did not mean that one was devoid of culture—a reminder that she felt should have come from the instructor. Other instructors did not seem to appreciate the ramifications of their actions for specific students. The 'privilege' exercise attempted by one instructor, for example, left a minority student feeling more isolated than before, even though it had obviously been introduced with good intentions.

When instructors were not prepared to facilitate difficult dialogues, their shortcomings negatively impacted the minority students in the class. Faculty should be thoughtful about the selection of materials they bring to class and the paradoxical effects these can have on students. When difficult dialogues arise in class, instructors should be prepared to facilitate conversations between students with different worldviews, rather than trying to dismiss an uncomfortable comment or divert the conversation to a safer topic. Genetic counseling programs should take responsibility for ensuring that those individuals who teach cultural competency classes are adequately trained in these skills, because when they are not, the burden of responding and educating their classmates falls disproportionately upon minority students.

Finally, by relying on the perspectives of minority students to educate classmates about their particular cultures, training programs are neglecting to adequately educate them about issues of systemic racism or structural barriers to accessing health care. Genetic counselors are not currently required to demonstrate competency in these topics (Accreditation Council for Genetic Counseling, 2019a), so training programs appear to be focusing instead on teaching students to provide culturally competent care at the level of individual patient-provider interaction. However, genetic counselors need to recognize the systemic barriers that prevent patients from presenting to clinic in the first place, not just provide culturally competent care to those who overcome those obstacles.

4.1 | Study limitations

There are several limitations to this study. First, this is a qualitative study, with results that reflect the perspectives of a racially and ethnically diverse group of participants who attended different training programs across the United States. As such, they reflect a wide range of perspectives and opinions, and are not directly comparable to each other. In addition, these perspectives cannot be generalized to all minority genetic counseling students.

Second, while focus groups have distinct advantages that led to our selecting them as our means of data collection, they also have drawbacks. Participants may selectively omit information due to concerns about confidentiality or provide answers that are more socially desirable.

Finally, we did not collect data from training programs about their cultural competency curriculum or directly observe any interactions between students and instructors. The information in this study is based on the recollections of participants and is subject to their retrospective interpretation of events. Similarly, interpretation of the participants' recollections is subject to the researchers' viewpoints and understanding.

4.2 | Educational implications

This study highlights room for growth in the model of cultural competency instruction utilized within genetic counseling training programs and suggests potential areas for improvement. First, training programs need to carefully evaluate the content of their cultural

competency curriculum. Coursework that reinforces stereotypes about particular racial or ethnic groups should be critically assessed for educational value. Rather than just teaching students how to provide care to specific non-majority groups, students should be encouraged to examine and address their own implicit biases and be educated about historic and structural factors that lead to healthcare disparities and social inequities.

Second, the format of the cultural competency instruction should be evaluated. Any context in which the instruction is predicated on students sharing their perspectives should be assessed to determine if it is disproportionately burdening students from non-majority cultures or reproducing inherited binary understandings of White students as 'neutral' or without culture and minority students as cultural 'others' who need to take action on behalf of their classmates' learning. All students should be recognized as possessing culture, and the culture of all students should be integrated into discussions. In addition, programs should ensure that support systems are available for students who may be negatively impacted by these discussions; these could include mentorship programs (such as those provided by the MGPN) or university counseling services.

Third, training programs should carefully evaluate the selection process for those who will be teaching cultural competency classes. Instructors should have sufficient expertise in the topic at hand so that students do not feel obligated to correct faulty information. In addition, they should be prepared to facilitate emotionally charged conversations that may arise when discussing race and social inequities. Genetic counseling programs may need to consider implementing additional training for their instructors or look to university or community resources for instructors already trained in these skills.

Finally, the conscripted curriculum may also impact students from other non-majority groups, such as individuals who identify as LGBTQ+ or of lower socioeconomic status. Training programs should consider the impact of the cultural competency curriculum on these students.

4.3 | Research recommendations

This study provides feedback about the cultural competency curriculum from the perspective of students who identify as racial or ethnic minorities. Future research could investigate the perspectives of other individuals, such as program directors, supervisors, non-minority students, or those who identify with other minority groups (e.g., LGBTQ+). Another approach would be to review cultural competency curricula on a program-by-program basis to identify 'best practices' that could be utilized across the field. Finally, developing training materials for use within programs or to train instructors would be valuable.

5 | CONCLUSIONS

This study investigated the training experiences of genetic counseling students who identify as racial or ethnic minorities, and found evidence of a conscripted curriculum. Compared to their White classmates, minority students are disproportionately burdened by expectations that they share their perspectives and experiences to educate their classmates about issues of race and ethnicity, resulting in feelings of frustration and exhaustion. Genetic counseling programs should critically examine their cultural competency curriculum to create a more equitable training environment and ensure that instructors are trained to facilitate difficult discussions about race and racism. The genetic counseling profession should consider modifying the practice-based competencies to include requiring students to demonstrate an understanding of how structural disparities impact access to health care.

AUTHOR CONTRIBUTIONS

Nikkola Carmichael contributed to the conception and design of this study. She recruited the participants, facilitated the focus groups, and analyzed and interpreted the data. She was also the primary author of this work. Shira Birnbaum contributed to the conception and design of this study. She assisted with the analysis and interpretation, as well as the writing and revision of this work. Krista Redlinger-Grosse contributed to the conception and design of this study. She assisted with analysis and interpretation, as well as the writing and revision of this work.

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COMPLIANCE WITH ETHICAL STANDARDS

Conflict of interest

Nikkola Carmichael, Shira Birnbaum, and Krista Redlinger-Grosse declare that they have no conflict of interest.

Human studies and Informed consent

This study was approved by the Simmons University IRB. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all participants included in the study.

Animal studies

No non-human animal studies were carried out by the authors for this article.

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Links to Additional Resources

Improving Diversity of the Genomics Workforce: A Workshop

- Bonham & Green, 2021. The genomics workforce must become more diverse: a strategic imperative. *The American Journal of Human Genetics* 108(1): 3-7. https://www.sciencedirect.com/science/article/pii/S0002929720304493

- Channaoui et al. 2020. Summary report of the 2019 Diversity and Inclusion Task Force of the National Society of Genetic Counselors. *Journal of Genetic Counseling* 29(2): 192-201. https://onlinelibrary.wiley.com/doi/full/10.1002/jgc4.1270

- Mann, S. 2020. Creation of the Minority Genetic Professionals Network to increase diversity in the genetics work force. https://onlinelibrary.wiley.com/doi/10.1002/jgc4.1248

- Rotenstein et al. 2021. Addressing workforce diversity – A quality-improvement framework. *Thr New England Journal of Medicine*. 384: 1083-1086. https://www.nejm.org/doi/full/10.1056/NEJMp2032224

- ASHG 2021 Meeting- Session on workforce diversity in genomics: Equity and the meaning of inclusion. https://www.ashg.org/meetings/2021meeting/attendees/schedule/