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# Improving Diversity of the Genomics Workforce: Proceedings of a Workshop in Brief (2022)

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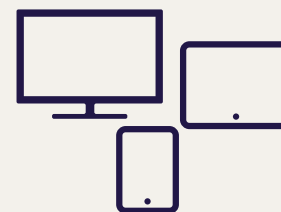
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# Proceedings of a Workshop

IN BRIEF

February 2022

## Improving Diversity of the Genomics Workforce

Proceedings of a Workshop—in Brief

In 2020, as part of its strategic planning initiative, the Roundtable on Genomics and Precision Health of the National Academies of Sciences, Engineering, and Medicine decided to explore four action-oriented focus areas for its activities over the coming 3 to 5 years (Ginsburg et al., 2021). These areas were driving innovation, shaping the policy dialogue, spurring the adoption of tools and approaches, and achieving equity. The roundtable began its exploration of the fourth of those thematic areas—achieving equity in genomics and precision health—by holding a workshop on October 5, 2021. That workshop, *Improving Diversity of the Genomics Workforce*, examined the current state of diversity of the genetics and genomics workforce; the structural and social factors associated with the lack of workforce diversity; the impact of diversity in the workforce on access to genetic services and patient outcomes; and possible actions that could lead to a more diverse, equitable, and inclusive genomics workforce.

### CURRENT STATE OF DIVERSITY OF THE GENETICS AND GENOMICS WORKFORCE

According to the 2021 professional status survey by the National Society of Genetic Counselors, 90 percent of genetic counselors in the United States are white, and the percentages of genetic counselors identifying as Black or Hispanic/Latino/Latinx<sup>1</sup> are not proportionally representative of the general U.S. population, said Sylvia Mann, the supervisor of the genomics section at the State of Hawaii Department of Health and a project director of the Western States Regional Genetics Network and Minority Genetic Professionals Network. Recently published surveys of the genomics workforce reveal that currently it is largely of European descent, female, working in metropolitan areas, and at academic medical centers (Jenkins et al., 2021; National Society of Genetic Counselors, 2021), said Altovise Ewing, a senior science leader at Genentech. Although the workshop discussions were focused on racial and ethnic diversity, other areas of diversity need attention as well, said Barbara Harrison, a genetic counselor and assistant professor in the Department of Pediatrics at the Howard University College of Medicine. These areas of diversity could include “gender, sexual orientation, immigration status, physical disability, [and] socioeconomic status,” said LaTasha Lee, the vice president for clinical and social research and development at the National Minority Quality Forum (NMQF). The racial and ethnic distribution among genetic counselors has not changed significantly over the past couple of decades, even though the general population of the United States has become increasingly diverse, Mann and Harrison both observed. Specifically, there has been only a 2 percent increase in racial and ethnic diversity since 2019, and in 2021, only 3 percent of genetic counselors identified as Latinx, which is in contrast with the general population, which is 18.3 percent Latinx based on the 2020 census, Harrison said.

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<sup>1</sup> Currently there is not a widely accepted or preferred term for Hispanic/Latino/a/x. However, to best reflect the language that was most often used by speakers, Latinx is used through the rest of the text to represent the Hispanic/Latino/a/x population.

## STRUCTURAL AND SOCIAL FACTORS ASSOCIATED WITH THE LACK OF WORKFORCE DIVERSITY

A range of barriers hinder the entry and retention of underrepresented<sup>2</sup> individuals in the health professions in general and in genetics/genomics in particular, Mann said. Potential students often cannot meet requirements for admission to health profession programs due to insufficient academic preparation (e.g., they might not have had access to relevant or sufficiently rigorous science classes at their school). A lack of awareness of career options and a lack of role models in the health professions are also barriers, she said. There are documented examples of poor advising by high school and college career advisors who do not guide underrepresented students towards careers in science, Mann added. Cost can be a barrier, and financial assistance for education is limited, especially for master's degree programs in genetic counseling. Underrepresented students must also contend with a lack of institutional and faculty support in training programs and negative stereotypes about their capabilities which can lead to imposter syndrome, she said. Underrepresented students continue to experience racism in training programs and clinical rotations, Mann said.

Beyond barriers for students, qualified job candidates are sometimes eliminated from consideration as a result of design flaws in the human resources screening process, said Omar Abdul-Rahman, the director of genetic medicine and a pediatric geneticist at the Munroe-Myer Institute of the University of Nebraska Medical Center. He became aware of this issue, he said, when some highly qualified candidates who were rejected by human resources reached out to him directly. There is a need to better understand institutional processes of screening applicants so that qualified diverse candidates are not excluded, he said.

### Impacts of Diversity in the Genomics Workforce on Patient Care

“The need for genetic professionals is just increasing faster than the rate of staffing and faculty [positions available] that are necessary to do it,” Abdul-Rahman said. There are often “bottlenecks” in the field of pediatric genetics because “geneticists can only see so many patients at a time.” Concurrently, the technology for delivering genetic care is advancing rapidly which could help to reduce disparities by increasing access to care. For example, the utility of whole-genome sequencing in acutely ill infants was shown to help clinicians reach diagnoses more rapidly (Farnaes et al., 2018). However, Abdul-Rahman said, using advanced diagnostic technologies can have unintended negative consequences for patients and their families if a diverse workforce of counselors and geneticists is not available. These diverse individuals can administer culturally relevant informed consent prior to whole-genome sequencing and counsel families on the results afterward (e.g., when someone is identified as a carrier of a particular genetic disorder), he said.

The importance of training providers who understand the culture, speak the language, and are trusted by traditionally underserved communities was highlighted by Mann. Longitudinal studies of medical school programs have shown that a more diverse student body results in long-term benefits for both the workforce and the populations it serves (Clayborne et al., 2021). Students from diverse programs, regardless of racial background, reported higher levels of both preparedness and desire to work with underrepresented populations. They also tended to feel more comfortable working with patients from diverse racial and ethnic backgrounds and were able to communicate more effectively, as evidenced by feedback from patients, Mann said. Furthermore, a more diverse student body and health care workforce result in both increased access to care and improved quality of care for underserved communities (Clayborne et al., 2021). “Having a diverse workforce is not just a nice thing to do,” Mann said, “Diversity leads to decreased health disparities and improves outcomes for minority patients.”

The benefits of patient and provider racial concordance<sup>3</sup> for people from underrepresented backgrounds were discussed by Lee. A clinical provider whose racial and ethnic background is similar to that of the patient is “more likely to present information in a culturally and linguistically sensitive and appropriate manner,” Lee said. Patients also tend to be more forthcoming and ask more questions when there is a concordant relationship with their providers. Patient-provider concordance is associated with improved care and outcomes (Jetty et al., 2021). In many cases, racial and ethnic minority individuals do not obtain genetic counseling due to a lack of awareness of these services (Saulsberry and Terry, 2013), and providers often do not take a full family history of disease, which could lead to a referral for genetic counseling, Lee observed. Other barriers for genetic counseling include limited access to services, socioeconomic issues, and lack of trust (e.g., concerns about who has access to their genetic information and how it might be used) (Saulsberry and Terry, 2013), Lee noted.

<sup>2</sup> In this proceedings in brief, the terms “underrepresented populations” or “underrepresented groups” are used to refer to groups of individuals with various identities discussed by the speakers, including African American or Black, Hispanic/Latino/a/Latinx, Native American (American Indians, Alaska Natives, and Native Hawaiians), and Pacific Islander.

<sup>3</sup> Racial concordance is when a patient and a provider have a shared racial identity (Jetty et al., 2021).

Investing in a more diverse genomics workforce is a societal imperative, Ewing said. A lack of diversity in the workforce dramatically limits the reach of genetic and genomic services and impedes inclusive implementation, she said. When racial and ethnic minority individuals are not referred for genetic services, they are excluded from precision care and preventative screening, which can perpetuate inequities in patient care and health outcomes. A lack of diverse population data from genetic screening also affects the development of equitable professional and practice guidelines. “In order to successfully conduct more inclusive science that leads to equitable solutions and outcomes for all populations, it is paramount that our medical and scientific genomics workforce reflect the world that we aim to serve,” Ewing said.

## Impacts of Diversity in the Genomics Workforce on Research and Education

The lack of diversity in the genomics workforce also slows the advancement of scientific knowledge and hinders the equitable application of scientific advances in genetics, Ewing said. A lack of a diverse genomics workforce limits who participates in genetics research, which can both restrict the generalizability of the findings to the broader population and exacerbate disparities in patient care and outcomes, both Lee and Ewing said. For example, most genome-wide association studies have been conducted in people of European descent, Lee said.

Establishing trust with communities came up throughout the workshop and was discussed by Mann, Ewing, and Lee. The American Society of Hematology (ASH) has worked to establish a sickle cell disease clinical trials network and disease registry. In discussions with sickle cell disease community members, it became apparent that they were more willing to share their personal medical information with the ASH team than with other organizations, Lee said. The team approached the project as a partnership with the community, and “the diversity in lived experience” of the team allowed them to better establish trust. Lee also highlighted a longitudinal study of the impact of the COVID-19 pandemic on underserved communities, conducted by NMQF as part of its Minority and Rural Coronavirus Insights Study (Landry et al., 2021). Building trust with communities is important, she said, and that study is being conducted in partnership with community-based organizations and federally qualified health centers (FQHCs).<sup>4</sup>

Understanding cultural issues is also essential to meeting the genetic and genomic needs of diverse populations, Lee said. As an example, researchers conducting genetic testing of newborns for sickle cell disease and trait in Africa initially faced resistance from mothers because of the social stigma associated with having a child with the disease. Understanding this cultural context was key to developing a successful public education campaign for the testing program, Lee said. The campaign emphasized that early testing provides knowledge and that the disease is not a “death sentence.” Success stories were also shared from families who found out their status and learned about the options available in their country for treatment of their babies.

Panelists discussed the impact of bias toward data from individuals of European descent in reference genomes, training sets for machine learning tools, and medical education materials. The bias in reference genomes affects the ability to counsel multiracial patients on their genetic screening results, particularly as it relates to understanding the risks posed by variants of uncertain significance, said Dallas Reed, the division chief of genetics at Tufts Children’s Hospital and the director of perinatal genetics at Tufts Medical Center. More diversity is needed among the participants in genomic research; therefore, more diversity is needed among those engaging the public about participating in research, she said. It is important that potential participants are comfortable asking questions about the research, understand that their genetic information is secure, and feel that the individuals performing the study are not taking advantage of them.

Diverse lived experiences and success stories from health equity spaces should influence what is deemed valuable in scientific thought, Ewing said. Engaging experts in health equity and health disparities issues can help inform research strategies. To ensure that equity is embedded end to end in the research process, from conception to the translation of results into policies, a diverse workforce is needed, she added. “There is power in diversity of thought,” Ewing said; increasing the diversity of lived experiences in the genomics workforce will stimulate innovation and promote equity in outcomes. “Not everything that is profitable is valuable,” said Damian Archer, the assistant dean for multicultural affairs and a clinical assistant professor of family medicine at Tufts University School of Medicine. It is important to ensure that what is being done is adding value; for example, in health care, value should be placed on ensuring a safe care environment that provides equitable treatment of genetic disorders by concordant clinical providers, Archer said. Institutional leadership needs to recognize that making changes that increase diversity, equity, and inclusion can have a cost for the institution, but the institution will provide greater value to society as a result of those efforts, he said.

The educational material presented to medical students offers one such example of an institutional change that could promote equity, Reed said. These materials often feature predominantly white case examples. Efforts are

<sup>4</sup> Federally qualified health centers (FQHCs) are health care providers that are community-based, providing primary care in underserved areas with funding from Health Resources and Services Administration Health Center Program (HRSA, 2018).

underway at the Tufts University School of Medicine to create an antiracist medical school curriculum that includes people of color in the images presented to students. This is important in genetics and dysmorphology<sup>5</sup> as students must be able to recognize features of a particular condition where phenotypes can present differently in different populations, Reed said. Similarly, the training databases for artificial intelligence tools need to be diversified to drive better identification of diagnoses based on dysmorphic features, she said.

A more diverse genomics workforce will generate more inclusive research questions and seek answers to problems of interest to broader populations, including those that are commonly underserved, underrepresented, and understudied in science and medicine, Ewing said. Conducting science that puts diversity, equity, inclusion, and justice (DEIJ) at the center may spur innovation and accelerate scientific progress. Moving forward, the genetics community needs to “take collective steps to reckon with its past, reinstate trust, and foster empathy” to restore relationships with underserved communities, Ewing said. Equity must be embedded into genetics research which includes engaging patients in linguistically and culturally relevant ways, she said.

## EXPLORING POTENTIAL ACTIONS THAT COULD LEAD TO A MORE DIVERSE, EQUITABLE, AND INCLUSIVE GENETICS AND GENOMICS WORKFORCE

Throughout the workshop, speakers discussed a range of potential interventions that could improve diversity in the genetics and genomics workforce, such as exposing secondary school and college students to potential careers in health-related professions, providing support and guidance to those applying to graduate programs and medical schools, and networking and mentoring to improve recruitment and retention of both students and professionals (highlights are presented in Box 1).

<sup>5</sup> Dysmorphology is the study of birth defects or alterations of typical morphology (Richtsmeier, 2017).

### BOX 1 SUGGESTED INTERVENTIONS TO IMPROVE THE DIVERSITY OF THE GENOMICS WORKFORCE PRESENTED BY INDIVIDUAL SPEAKERS

- **Raising awareness.** There is much work to be done to raise awareness of genetics and genomics careers among students, parents, educators, and counselors. High school and college students could be exposed to career options in genetics and genomics through in-person engagement and outreach. (Abdul-Rahman, Harrison, Mann, Reed)
- **Establishing holistic admissions processes.**<sup>a</sup> Institutions can reevaluate the factors they consider in admissions decisions (e.g., the weight given to standardized test scores) and what constitutes a “competitive” applicant to a genetics training program in order to develop a more holistic and inclusive approach to admissions. (Abdul-Rahman, Harrison)
- **Creating internship and shadowing opportunities.** Institutions could establish and provide internship and shadowing experiences for prospective applicants to genetic counseling programs and facilitate internships in other genetics and genomics fields through industry. (Harrison, Reed)
- **Fostering safe spaces.** Institutions could ensure a safe, supportive environment for underrepresented students through the implementation of institutional policies, the employment of diverse faculty, training programs that include discussions, clear reporting guidelines and outcomes, and other activities that promote diversity, equity, inclusion, and justice. (Mann)
- **Providing mentorship.** Mentors can support and guide students from diverse backgrounds in, for example, learning about careers in genetics and genomics, assembling competitive applications, and navigating training programs. Mentoring and networking can help retain practicing underrepresented genetic professionals and support their career development. (Abdul-Rahman, Harrison, Lee, Mann, Sol)

*continued*

## BOX 1 CONTINUED

- **Reimagining educational pathways.** Broadening both the roles for individuals in the genetics and genomics workforce (e.g., genetic counseling assistants) and the pathways for training and academic instruction (e.g., distance learning, combined degree programs) would create a novel pipeline that could lead to an increase in workforce diversity. Training could also be adapted to better develop untapped talent in communities and to prepare students to succeed in the workplace. Work with institutions where underrepresented students attend (such as historically Black colleges and universities) to create pipeline programs. (Abdul-Rahman, Archer, Harrison, Mann, Reed, Sol)
- **Influencing policy.** Certified genetic counselors could be recognized as health care providers by Medicare so that they can be reimbursed for providing services. More appropriate reimbursement for all genetics professionals would positively affect salaries and would allow more rural hospitals to offer genetics services. Student loan forgiveness programs and funding for programs that support racial and ethnic minority participation were also suggested. (Abdul-Rahman, Ewing, Harrison, Lee, Mann, Reed)
- **Engaging industry.** Developers and providers of genomic tools, technologies, services, and written materials could recognize the language and cultural needs of diverse patient populations and adapt their products accordingly in order to increase accessibility and inclusion. (Reed)

This list is the rapporteurs' summary of points made by the individual speakers identified, and the statements have not been endorsed or verified by the National Academies of Sciences, Engineering, and Medicine. They are not intended to reflect a consensus among workshop participants.

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<sup>a</sup> UNMC High School Alliance: Health Sciences Enrichment Program, University of Nebraska Medical Center, <https://www.unmc.edu/alliance> (accessed November 10, 2021).

## Raising Awareness of Careers in Genetics and Genomics

Throughout the workshop, panelists discussed raising student, parent, and educator awareness of career pathways in genetics and genomics. Although some prospective students might become aware of genetics through a paragraph in a textbook, social media outreach, or media coverage of celebrities undergoing genetic testing, studies have shown that in-person engagement is the most effective way to reach undergraduate and secondary school students (Price et al., 2020). Most underrepresented students that Harrison has talked with were not aware of genetic counseling as a career option “until they happened upon it,” Harrison said, often through a classroom presentation by a genetic counselor or shadowing or internship opportunities. “Brochures are not enough,” she asserted. Many genetic counselors learned of the field because of a family member receiving genetic counseling and being exposed to the career as an option, Mann added. Engagement activities should be targeted towards institutions where underrepresented students attend, such as historically Black colleges and universities (HBCUs), Harrison suggested. When promoting a genetic counseling degree, the range of roles that individuals can fill could be discussed. These roles include working in laboratories, the public health arena, or even departments of education supporting children with genetic conditions who might have special educational needs.

Reed emphasized that awareness of the field of clinical genetics must be raised, even among professional medical colleagues, who often have a limited understanding of or even misperceptions about what a medical geneticist does. Although clinical geneticists' roles are entirely patient-oriented, other physicians often think geneticists are “in a lab doing something with editing DNA.” Furthermore, efforts could ensure that physicians are better informed about when it is appropriate to refer their patients to a clinical geneticist or to order genetic tests. The lack of awareness about when it is appropriate to recommend genetic tests or counseling can lead to bias in genetic screening, she said. Genetics is usually taught during the first year of medical school and not covered again although “genetics is infused in every single part of medicine and research,” Reed noted.

## A More Holistic Approach to Graduate Admissions

Another key action would be providing support during the application process for students interested in pursuing a career in genetic counseling, Harrison said. While mentoring is helpful for any student applying to a genetic

counseling program, it is particularly important for first-generation college students or those who have relatively few resources or relevant experiences. Applicants from underrepresented backgrounds can face challenges based on their academic capital. Academic capital is a term that refers to the social processes that students need in order to maneuver through and succeed in higher education (Huang, 2021). Challenges related to academic capital can include navigating the application systems, meeting application costs, and securing in-person shadowing experiences that make genetic counseling applicants more competitive (Huang, 2021). In addition to preparing prospective applicants, there is a need to reassess what makes a “competitive” genetic counseling applicant and to place more value on experiences that are more inclusive and accessible to a broader population, Harrison suggested. For example, virtual case conference experiences, which increased significantly due to the COVID-19 pandemic, “should be broadly accepted in lieu of actual in-person shadowing experiences,” she said. Institutions “should be part of the solution” and work to create or provide internship and shadowing experiences for prospective applicants, Harrison suggested.

The need for a more holistic admissions process was reiterated by Abdul-Rahman. The Medical College Admissions Test (MCAT) was designed to predict success in medical school coursework, and “the range of scores that predict success is actually quite wide,” he said. However, medical schools focus on students with top scores, as the average MCAT score of the incoming class weighs heavily in medical school ranking systems. Some ranking systems (e.g., the one that is provided by *U.S. News & World Report*<sup>6</sup>) recently added a diversity score for medical schools, which could incentivize schools to improve diversity, Abdul-Rahman said. “Our future genetic counselors and geneticists are out there,” Harrison said, adding that “we need to make them feel included, we need to let them know that their perspectives are wanted at our tables.”

## Creating Supportive Education and Training Environments

To foster support of underrepresented students in the health professions, programs need to ensure they provide a “safe space” for students, Mann said. Specifically, genetics training programs need to “create an environment that supports diversity, equity, inclusion, and justice,” she said. This includes establishing relevant institutional policies on DEI, employing diverse faculty and staff, mandating training on DEI issues, and developing systems that support interracial learning and interaction, Mann continued. Promoting open communication and committing to address identified issues are also essential, as students often fear retaliation if they speak out about concerns. Finally, she said, creating a safe space requires continuous evaluation and improvement. Institutions should not increase their recruitment of underrepresented students until such measures to ensure safe spaces are in place, Mann cautioned.

Harrison discussed establishing genetic counseling programs at HBCUs and other minority-serving institutions as a solution to increase workforce diversity. The Howard University Genetic Counseling Training Program, which ran from 1980 through 2014, is an example of a graduate program with a holistic admissions process and a supportive educational environment, she said. Many genetic counseling students reported applying solely to Howard University, Harrison added. Outside the program, however, students often reported feeling unwelcome in their clinical rotations and experiencing microaggressions, she said. Alumni of the Howard program are “trailblazers,” many of whom are now working in their communities as counselors and in “nontraditional” roles (e.g., laboratories, public health), Harrison said. Xavier University of Louisiana, another HBCU, has announced it is establishing a graduate program in genetic counseling, both Harrison and Lee noted.

## Mentoring for Recruitment and Retention

Speakers shared examples of several organizations that are taking action to recruit and support underrepresented students and professionals, including the Minority Genetic Professionals Network (MGPN), the Genetics Opportunity, Learning, Development, and Empowerment Network (GOLDEN), and the University of Nebraska Medical Center (UNMC) High School Alliance (see Box 2).

Once a high school or undergraduate student is aware of and interested in a genomics career, mentoring is important to nurture that interest, Harrison said. Approaches to recruiting and mentoring diverse students, especially given that the majority of current genetic counselors are white and do not share these students’ backgrounds or experiences, were discussed by the panelists. “You don’t have to be a minority person to mentor a minority student,” Mann said. The MGPN provides ally training because white colleagues are often eager to help but are unsure of how best to do so and are concerned about doing something wrong, she explained. Mentors need to be open, transparent, and

<sup>6</sup> “Most Diverse Medical Schools,” *U.S. News & World Report*, <https://www.usnews.com/best-graduate-schools/top-medical-schools/medical-school-diversity-rankings> (accessed November 10, 2021).

## BOX 2

### EXAMPLES OF PROGRAMS SUPPORTING THE CAREER DEVELOPMENT OF UNDERREPRESENTED STUDENTS AND PROFESSIONALS AS PRESENTED BY INDIVIDUAL SPEAKERS

The *Minority Genetic Professionals Network (MGPN)*<sup>a</sup> is a project of the Western States Regional Genetics Network, funded by the Health Resources and Services Administration. The network is intended to “increase access to genetic services and education for racial and ethnic minority families by increasing the number of underrepresented genetics providers,” Mann explained. It focuses on supporting the recruitment and mentoring of underrepresented trainees and practicing professionals. MGPN activities include outreach, networking, mentoring, interview practice, research support, self-care, and professional development. MGPN also focuses on high school students so that they are aware of genetic counseling as a career option when considering colleges and when selecting college classes (to ensure that the prerequisites for application to graduate programs are met). Members of local and regional MGPN groups participate in high school and undergraduate local, regional, and national career fairs to raise awareness of all genetics professions. Career fairs went virtual during the COVID-19 pandemic, and there were more than 1,400 attendees at the second annual MGPN virtual career fair for genetic counseling, Mann said.

The *Genetics Opportunity, Learning, Development, and Empowerment Network (GOLDEN)*<sup>b</sup> was co-founded by Barbara Harrison and Grace-Ann Fasaye and is funded by the New York Mid-Atlantic Caribbean Regional Genetics Network.<sup>c</sup> The mission of GOLDEN is to increase the number of Black genetic counselors by increasing awareness of the profession and mentoring prospective applicants. The program has reached out to HBCUs and to high schools and community colleges with high racial and ethnic minority student representation via information sessions at schools and through social media. Several 2-minute videos and an hour-long presentation on pursuing a genetic counseling career are available. Importantly, recruitment materials feature Black genetic counselors and students, so that prospective students can see themselves in these roles, Harrison said. Virtual mentoring events include case conferences with cases that address DEI, interview practice, and a review of personal statements for applications. There are also financial incentives available to students to help offset application costs and to provide compensation for the genetic counselors who share their time and talents.

The *UNMC High School Alliance*<sup>d</sup> was established a decade ago by the University of Nebraska Medical Center (UNMC) in association with the Omaha Public School District to draw junior and senior high school students from diverse background to careers in the biomedical sciences. Each year, about 50 students who are selected for this immersive academic enrichment program spend 2 hours each school day at the UNMC campus taking classes taught by UNMC faculty. Students choose from a range of health care and research topics, including biomedical research, human anatomy, human genetics, public health, pharmacy, imaging, and others. Students also attend a weekly health careers exploration session, an opportunity for professionals to engage with students about careers in genetics, Abdul-Rahman said. Of the 500 students who have completed the Alliance program, 97 percent went on to attend college, 70 percent pursued a health-related major, and more than half went into a health-related profession (Davies et al., 2022). In August 2020, UNMC launched an online health science curriculum that is available for use by teachers nationwide.

<sup>a</sup> Minority Genetic Professionals Network, <https://mgpn.chronus.com> (accessed November 10, 2021).

<sup>b</sup> GOLDEN interest form, [https://docs.google.com/forms/d/e/1FAIpQLScep1CbgAZPKwuT\\_Jq3D7FcnVLRDGCnk9FF\\_VPVMOnIznk59Q/viewform?vc=0&c=0&w=1&flr=0](https://docs.google.com/forms/d/e/1FAIpQLScep1CbgAZPKwuT_Jq3D7FcnVLRDGCnk9FF_VPVMOnIznk59Q/viewform?vc=0&c=0&w=1&flr=0) (accessed November 10, 2021).

<sup>c</sup> NYMAC Regional Genetics Network, New York Mid-Atlantic Caribbean Regional Genetics Network, <https://nymacgenetics.org> (accessed November 10, 2021).

<sup>d</sup> UNMC High School Alliance: Health Sciences Enrichment Program, University of Nebraska Medical Center, <https://www.unmc.edu/alliance> (accessed November 10, 2021).

willing, Mann added. “Being genuine” in interactions with students is an important component of thoughtful mentorship, Harrison emphasized. Mentors can partner with individuals from the community to determine the most effective approach for engaging students, she added. For example, engagement might be done in association with a champion from the faculty, such as a biology teacher from an underrepresented population. Allies can help not only in recruiting students but also in fostering the retention of practicing underrepresented genetic counselors in the workplace. Genetic counselors in general “have a good heart, and they’re inherently empathetic, and they’re inherently good



listeners,” Abdul-Rahman said, and these skills also make for a good mentor, regardless of one’s background. Another role for mentors is guiding students in writing their application essays to best express their uniqueness, he added.

People can certainly have more than one mentor, Harrison said. For example, someone might be mentored by both a genetic counselor who is white because of their specific expertise and someone from an underrepresented background (not necessarily a genetic counselor) who can support and offer advice on issues that underrepresented professionals face in the workplace. As the first African American student in her program, Harrison found a social worker in a sickle cell clinic to be a valuable mentor for issues she was facing as an underrepresented student (e.g., microaggressions, feeling “less than”). An example of a successful mentorship program in a pediatrics department consists of junior faculty members having a personalized committee of mentors, Abdul-Rahman said. Each mentor on the committee, selected in consultation with the mentee, represents an area of the mentee’s interest (e.g., clinical focus, research interest). The committee also includes a promotion expert to guide the mentee in developing their promotion portfolio. Over time, successful mentees become mentors for the next generation, creating a cycle of success. As more people from diverse backgrounds advance, they attract individuals from diverse populations to the field, he added.

Lee emphasized the importance of mentoring students from diverse backgrounds, especially in the current absence of genetic training programs at HBCUs and similar minority-serving institutions. Lee related how, as a high school student, she benefited from being mentored by graduate students and faculty of color in the sciences through the Louis Stokes Alliance for Minority Participation (LSAMP)<sup>7</sup> program at Florida A&M University (an HBCU). To help recruit new people to the field of genomics, mentors could be strategically placed. For example, mentors from the genetics workforce could be engaged with primary care where more people may be inspired to pursue genomics, suggested Catalina Sol, the executive director of La Clinica del Pueblo. While clinical precepting and mentoring the next generation are expected as part of the job, these activities need to be valued in the form of appropriate compensation, she added.

Panelists discussed the importance of avoiding “burnout” in the workplace. “You have to not give so much of yourself that you have nothing left,” Harrison said. Giving others who have less experience the opportunity to take on some tasks, empowering the next generation to step up, and being available to support them as needed were suggested by Harrison as ways to avoid burnout. Both Abdul-Rahman and Harrison spoke about the value of having a network of supportive colleagues to communicate with when facing challenges. The MGPN has connected colleagues who support each other as they work to enact change and often face the same frustrations, Harrison added. The positive impact that the MGPN is having for diverse students applying to genetic counseling training programs gives Mann energy, she said. The value of activities such as spending time with family and engaging in hobbies to unplug and de-stress was also highlighted by panelists.

## Reimagining Educational Pathways to a Genetics and Genomics Career

The Bureau of Labor Statistics projects that the genetic counseling profession will grow by more than 26 percent over the next decade (BLS, 2021), which is more rapid than for most other professions, Ewing reported. This growth presents an opportunity for genomic professionals to work together to improve the diversity of the workforce and ensure that genetic services are accessible across demographics and geographies. “Representation matters,” Ewing said, and there must be investment in “pipeline programs, summer programs, scholarships, along with payment incentives for individuals to pursue genomic professions and serve in the areas with the greatest unmet medical need and inequitable outcomes.” Leveraging technology, creating new professions, developing the existing workforce of allied health, and supporting staff to fill more advanced roles were methods discussed to evolve the pathways to a genomics career. Developing these pathways can help meet the growing demand and support workforce diversity in genomics. There is value in distance learning models for students from diverse backgrounds because many cannot, or do not want to, move away from their families and communities to pursue a genetics training program, Mann explained. Distance programs allow them to “train where they are, and then work in that community,” she said.

The relatively new role of genetic counseling assistant can be both a career option and a pathway to becoming a genetic counselor or a geneticist, Mann said. Training as a genetic counseling assistant allows students to earn a good salary working in the field of genetics and to gain valuable experience should they choose to continue their education in genetics. Training underrepresented students to become genetic counseling assistants is one way to rapidly increase the numbers of genetics professionals as well as the diversity of the genetics staff available to help meet the needs of diverse patients and families, Mann added. There is also a need for more providers who are culturally and linguistically concordant with patients from non-Westernized communities, but standardized admissions testing, training programs, and

<sup>7</sup> “Louis Stokes Alliances for Minority Participation,” National Science Foundation, <https://beta.nsf.gov/funding/opportunities/louis-stokes-alliances-minority-participation> (accessed November 10, 2021).

licensing exams are all developed for Westernized trainees, Mann said. This creates barriers for promising students from non-Westernized communities who might not have strong English proficiency. Alternative pathways are needed to train these students who could then provide culturally competent care to their communities, she suggested.

There are lessons to be learned from how HBCUs have succeeded in increasing the number of Black applicants to U.S. medical schools, Harrison said. As has happened with existing pipeline programs from HBCUs to medical schools, creating HBCU pipeline programs for genetic counseling might increase the number of qualified underrepresented applicants to these educational programs, she suggested. The misconception some hold that HBCUs and similar institutions have lower criteria for admission and that students are therefore less prepared for success in rigorous graduate programs was dispelled by Harrison. Although some HBCU graduates might have lower mean scores on standardized graduate school admissions tests (e.g., Medical College Admission Tests or Graduate Record Examinations), studies have shown that the holistic approach to admissions and the supportive environment at HBCUs produce graduates who excel in medical school (Capers and Wey, 2015). Abdul-Rahman referred to the National Human Genome Research Institute (NHGRI) action agenda for increasing the diversity of the genomics workforce, which outlines milestones for building the pipeline, beginning with very early exposure to careers in genomics (Bonham and Green, 2021). “If you start the pipeline sort of halfway between the oil field and the port, you’re only going to get a trickle in,” he said. He also spoke of the importance of going where you can make the biggest difference.

Dual-degree programs in genetic counseling and another allied health field (e.g., public health or nursing) can help to raise awareness of genetic counseling as a career option and can be leveraged to improve diversity in the genomics workforce, Harrison said. Multidisciplinary training can also provide opportunities for genetic counselors to attain a doctoral degree, she added. Genetic counseling is currently a terminal master’s degree, and studies of why students pick certain careers over others have found that this limitation dissuades some students from pursuing genetic counseling (Schneider et al., 2009). Creating combined M.S./Ph.D. programs in genetic counseling and another health field would help attract highly motivated students from diverse backgrounds to the field of genetics. Furthermore, a streamlined, direct pathway from a bachelor’s degree in genetic counseling to a medical degree, modeled after other combined B.S./M.D. programs, could be designed, Harrison suggested. There are also ongoing discussions of how to establish combined M.D. programs, such as pediatrics and genetics, to reduce the number of years in training and residency. A combined B.S./M.S. degree for genetic counselors, as is done in other fields (often continuing straight through in 5 years at one institution, rather than 4 years for the B.S. followed by 2 years for the M.S.) may also be beneficial in terms of reducing the number of years of tuition that must be paid to obtain the proper degrees, Abdul-Rahman suggested.

The value of recruiting nontraditional students<sup>8</sup> to the genomics workforce was discussed by Sol. Workshop participants were encouraged to consider the existing workforce of allied health and support staff as a “working pipeline.” This strategy to develop a more diverse workforce trains people from the community to fill critical gaps in the local health care workforce while they continue to work at their current jobs, Sol said. “I think that we’ll have to give up some of our ideas of what a worker is and perhaps the academic institutions will have to give up some of their ideas as to what learning looks like,” she said.

As an example, Sol described La Clinica del Pueblo, an FQHC serving a predominantly Spanish-speaking immigrant Latinx population in Washington, D.C., and Prince George’s County, Maryland. All of the more than 100 direct service staff are Spanish-speaking, and all but a few are immigrants or children of immigrants. Many of the staff at La Clinica del Pueblo are immigrants who were simply seeking a stable job with benefits but “found their calling” in the health field, Sol said. Some support staff, with assistance from managers and motivation from their families, have trained to become nurses, dedicating themselves to achieving this goal over the span of 5, 10, or even 15 years, she said. Staff who have strong ties to the community and who see the impact of crises such as the COVID-19 pandemic on their family members and community are very committed, and they often see it as their personal mission to work at the clinic, Sol said. With the right support and structure, multilingual staff, who are often called upon to serve as interpreters for important medical conversations, might be inspired and train to advance to a higher level of work within the field of genomics, she added.

Many of the younger staff at La Clinica del Pueblo have been motivated to pursue health careers because of their personal family experiences, Sol said. For example, many have been interpreters for their parents for medical appointments or have helped family members with health concerns navigate the health system. Many promising young people in the community have family commitments and economic challenges that prevent them from directly pursuing an education in a health or medical field, she said, but gaining work experience at an organization such as La Clinica del Pueblo can help to set them on the path.

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<sup>8</sup> Nontraditional students work full-time before or during college.

It is important to identify and address the unique challenges and barriers that students from diverse backgrounds will face when they enter a workforce that remains inequitable, said Archer, who highlighted the need to address such questions as, where does the pipeline or pathway lead, and what bridges need to be built to enable students to perform well and be successful? Leadership must be truly committed to investing the time and resources required to ensure that everyone has opportunities to maximize their potential and that the focus of the workplace is providing the highest-quality care, he said. People from underrepresented backgrounds face more barriers in the workplace due to the persistence of systemic racism, so they must have more resilience, Reed added. Recruiting directly from diverse communities establishes a workforce with strong ties to patients of those communities and can help foster that resilience, she said. To generate effective solutions, it is important to consider real-world data on how different communities, populations, or individuals in different locations engage with different types of health care professionals, Ewing suggested.

## Policy Considerations

From a policy perspective, one action that could support building a more diverse workforce would be to have certified genetic counselors recognized as health care providers under Medicare, which would allow them to be reimbursed for providing services, Mann said. Legislation on this issue, the Access to Genetic Counselor Services Act of 2021,<sup>9</sup> was re-introduced in Congress this year, and Ewing called on the genetic societies to advocate for passage of the act. Recognition of genetic counseling services under Medicare could have a cascading effect, leading to similar recognition and reimbursement by Medicaid and private payers, Mann suggested. When organizations know they can be reimbursed for these services, they are likely to hire more genetic counselors, creating more jobs and internship opportunities for the next generation of genetic counselors as well as opportunities to build a diverse workforce, she said.

Poor reimbursement for time spent providing genetics services is “one of the root causes of the undervaluing of genetics in general in medicine,” Reed said. Poor reimbursement results in poorly paid clinical genetics providers, which dissuades students from entering the field, and many spots in excellent medical genetics programs go unfilled, she said. Of those that do pursue clinical genetics in the United States, very few identify as Black, Reed noted from her own count. Poor reimbursement also affects where services are located, and most clinical genetics programs are found at tertiary academic centers that can afford to maintain a program (Jenkins et al., 2021). Appropriate reimbursement for clinical genetics care could encourage more people to enter the field and allow more rural hospitals to offer genetics services, thereby expanding access to more diverse populations.

Another policy action that could support a diverse workforce would be to create student loan forgiveness programs for new genetic counseling graduates who go on to work with underserved populations, similar to the existing programs for other types of health care providers, suggested Mann and Harrison. Lee stressed the need for additional funding for programs that support participation of underrepresented individuals (such as LSAMP).

## A Role for Industry in Supporting a Diverse Workforce of Providers

There is an opportunity for companies to sponsor students at HBCUs for summer internships and summer scholars programs in order to build interest in the genetics and genomics field and grow the workforce, Lee suggested. Industry also has a role to play in expanding access to genetics services, Reed said. Industry partners including payers, need to work with providers to understand the language and cultural needs of their patient populations when creating new tools and written materials, she said. For example, artificial intelligence tools are being developed to identify patients who might benefit from genetic screening; however, most of these tools are available in English only, or perhaps also in Spanish. Similarly, many patients face language barriers when dealing with insurance coverage for genetic testing or following through when their doctor orders testing. “Many patients who don’t speak or read English . . . fall through the cracks,” Reed said.

## CLOSING REFLECTIONS

Topic areas that were raised for the roundtable to explore further were reviewed by Katherine Johansen Taber, the vice president of clinical product research and partnerships at Myriad Genetics. For example, the roundtable might consider helping to amplify the impact of the diversity efforts discussed during the workshop or fostering collaboration among institutions so that there is consistency across institutional DEI initiatives, Taber said. Taber also reiterated a suggestion raised by Mann to convene organizations focused on DEI, which could consolidate efforts and resources to achieve

<sup>9</sup> H.R.2144—Access to Genetic Counselor Services Act of 2021, congress.gov, <https://www.congress.gov/bill/117th-congress/house-bill/2144?q=%7B%22search%22%3A%5B%22hr+2144%22%5D%7D&r=1&s=1> (accessed November 10, 2021).

greater results than each institution could achieve alone. Taber emphasized a suggestion from Harrison, saying that the roundtable could also encourage collaboration among the genetic counseling, genomics, and clinical genetics communities to conduct coordinated outreach to high schools and colleges about career opportunities in genetics and genomics broadly. Convening stakeholders to further explore the issues of payment and reimbursement that disincentivize careers in genetics is another area that could be considered, Taber said. Discussions are also needed concerning how to provide faculty with protected time for DEI activities, Taber said, reiterating suggestions offered by Abdul-Rahman. Alternative educational pathways and programs could be explored to understand which programs or efforts result in improved outcomes and how to foster uptake, Taber continued. Finally, stakeholders could be convened from industry to learn about and encourage their efforts to promote inclusion and diversity in their research, products, communications, and training opportunities, she said.

In closing the workshop, Chazeman Jackson, the senior director of diversity, equity, and inclusion for the American Society of Human Genetics, highlighted some of the other points made throughout the workshop. There is evidence that diversity in the health care workforce improves access and provides culturally appropriate care for patients, she said. Jackson reiterated Mann's comment that "having a diverse workforce isn't just a nice thing to do" as well as Ewing's statement that investing in a more diverse genomics workforce is a "societal imperative." The workforce should reflect the population it serves; otherwise, the reach of genomic services is limited, scientific advances are impeded, and inequities in patient care and outcomes are perpetuated, Jackson summarized. ♦♦

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