“How Disparities and Workforce Diversity Impact Cancer Patients and Caregivers” (Eugene Manley, PhD) [#111]

Brad Power and Emily Kim
August 28, 2024

“The mission of SCHEQ is to increase some workforce diversity and improve outcomes for underrepresented, underserved, and marginalized populations navigating the cancer care continuum. The vision long term is to have a trained workforce that reflects the populations having the greatest disparities, and to have increased cancer awareness and survivorship for all.” – Eugene Manley, PhD

Meeting Summary

Black and Hispanic patients face all of the challenges that other cancer patients face: emotional distress and anxiety, lack of knowledge about their disease and testing and treatment options, access to information and therapies, and the complex and dis-integrated medical and payment system. People of color face added challenges: a medical system with doctors who don't look like them and understand their issues, medical databases that don't include a representative sample of people of their background, a history of mistreatment by the medical system which has created a culture of skepticism and avoidance, and a culture of not openly discussing health issues.

Eugene Manley, PhD, the Founder and CEO of the STEMM & Cancer Health Equity (SCHEQ) Foundation, is uniquely qualified to explore these challenges and offer solutions. The mission of SCHEQ is to increase STEMM (Science, Technology, Engineering, Math, and Medicine) workforce diversity and improve outcomes for underserved populations navigating the cancer care continuum. By training, he is a mechanical engineer, biomedical engineer, and cell and molecular biologist with expertise in musculoskeletal biology, cancer biology, and biomechanics. He also happens to be a first generation scholar from inner city Detroit, so he has seen and overcome many barriers along the way. He transitioned to the nonprofit space and worked for the American Association for Cancer Research and two lung cancer patient advocacy organizations in roles spanning fundraising, grant administration, mentorship and training program development, career development award creation, health equity, and advocacy for underserved patients navigating the lung cancer care continuum. He still partners with institutions to publish studies on the lack of diversity in lung cancer cell lines and the experiences of black patients navigating lung cancer screening.

He serves on local, national, and international organizations offering his unique insights. He is a member of the National Lung Cancer Roundtable Stigma & Nihilism and Health Equity Task Forces. He also is a member of the PCORI (Patient Centered Outcomes Research Institute) Healthcare Delivery and Disparities Research (HDDR) Advisory Panel, and serves as a Patient Grant Reviewer. At a local level he is a member of the Stony Brook Medical Center Community Advisory Council and sits on the Advisory Board for Philly Student Doctors.

What are the unique challenges that Black and Hispanic cancer patients face?

“How Disparities and Workforce Diversity Impact Cancer Patients and Caregivers” (Eugene Manley, PhD) [#111]

- Low representation in clinical trials (often less than 4% participation)
- Limited access to comprehensive biomarker testing
- Higher likelihood of being underinsured or uninsured; “Financial toxicity” of cancer treatments
- Lack of diverse healthcare providers and medical staff
- Systemic bias and racism in healthcare delivery
- Limited information and resources in their communities
- Digital divide preventing access to health information
- Cultural barriers that discourage discussing health issues

What can Black and Hispanic patients and their loved ones do to overcome their unique challenges in navigating cancer care?

- Be an active advocate for yourself by seeking second opinions, asking about all available treatment options, requesting comprehensive biomarker testing, and understanding your full range of healthcare choices.
- Join supportive communities like the new "Shades of Color" Facebook group for black and Latino lung cancer patients, advocacy groups focused on specific cancer types, and patient support networks that provide information and resources; share your experiences to help other patients.
- Educate yourself by attending health equity summits and webinars, using digital health tools and resources, learning about clinical trials and screening guidelines, and understanding your specific cancer's biomarkers and treatment options.
- Seek out healthcare providers who understand your community's needs.
- Investigate financial support for treatments, e.g., sliding scale or community health center options.

What are the core areas that need to be addressed at a systems level to make change for people of color?

- Increase STEMM (Science, Technology, Engineering, Math, and Medicine) access and exposure for diverse scholars at early ages so they know they can go into STEMM fields.
- Develop and implement comprehensive mentorship, training, professional development, workshops, and wrap-around skills to help diverse scholars from undergrad through early career faculty navigate their degrees, career transitions, and set them up to be more successful professionally.
- Create infographics with diverse representation to break down basic medical information and then cancer information.
- Have patients advocate for the care they should get versus what they do get.

How can you learn more about racial disparities in cancer care and how to improve outcomes for people of color?

- See the work of SCHEQ (STEMM and Cancer Health Equity) to increase STEMM (Science, Technology, Engineering, Math, and Medicine) workforce diversity and improve outcomes for underrepresented, underserved, and marginalized populations across the cancer care continuum

- Contact Dr. Manley at EManley@scheq.org
- Research Rabble Health which is using digital tools and partnerships with pharmaceutical companies to improve access to care for underserved communities

“How Disparities and Workforce Diversity Impact Cancer Patients and Caregivers” (Eugene Manley, PhD) [#111]

Meeting Notes

KEYWORDS

patients, eugene, talk, cancer, lung cancer, people, work, trials, rochelle, black, community, screening, care, issues, disparities, representation, populations, sarcomas, health, prostate cancer

SPEAKERS

Eugene Manley (47%), Brad Power (24%), Rochelle Prosser (10%), Tucker Herbert (5%), Frank Nothaft (5%), Chris Apfel (3%), Ryan Moon (2%), Rebecca Driscoll (2%), Brian McCloskey (1%)

SUMMARY

Eugene Manley is the founder of the STEMM & Cancer Health Equity (SCHEQ) Foundation. Its mission is to increase STEMM (Science, Technology, Engineering, Math, and Medicine) workforce diversity and improve outcomes for underserved populations navigating the cancer care continuum. Health inequities cost $320 billion annually and lead to $42 billion in lost productivity. There is a lack of diversity in clinical trials, with only 3-4% black participation in lung cancer trials. Minorities are underrepresented in STEMM fields and need better mentorship. Digital tools and community outreach can improve access and advocacy. COVID-19 reduced cancer screening rates. Underserved communities need financial and informational support.

OUTLINE

Introductions

- Dr. Eugene Manley, the founder and CEO of the STEMM and Cancer Health Equity Foundation, talked about equity in cancer care.
- He trained as a mechanical engineer, biomedical engineer, and cell and molecular biologist.
- He has worked in musculoskeletal biology, biomechanics, and cancer biology, specifically lung and breast cancer.
- He transitioned to the nonprofit space, working at the AACR, Lung Cancer Research Foundation, and Lungevity.
- Diverse scholars in academic fields face challenges, including a lack of diversity in leadership and mentorship.

Health Inequities and Clinical Trial Diversity

- Dr. Manley discussed the economic impact of health inequities, citing $320 billion annually and $42 billion in lost productivity due to racial and ethnic disparities.
- He mentioned the lack of diversity in clinical trials, with the Acute View report showing the lowest trial diversity in a decade.
- He pointed out the bias and racism in care delivery, affecting underserved communities and patients who do not speak English.
- He emphasizes the need for diverse teams and accurate representation in clinical trials to improve outcomes for all populations.

“How Disparities and Workforce Diversity Impact Cancer Patients and Caregivers” (Eugene Manley, PhD) [#111]

Mission and Objectives of the STEMM and Cancer Health Equity Foundation

- Dr. Manley outlined the mission of the foundation: to increase workforce diversity, improve outcomes for underserved populations, and enhance research impact.
- The foundation aims to support diverse scholars from K-12 through academic training, providing exposure, access, and mentorship.
- The foundation also focuses on improving outcomes for underserved populations by providing information and resources.
- He highlighted the importance of enhancing research that impacts these populations and the need for a trained workforce that reflects the communities they serve.

Data on Representation in STEM and Clinical Trials

- Dr. Manley presented data from the NSF, showing the lack of representation of American Indian or Alaskan Native, African Americans, and Hispanics in biology degrees and PhDs.
- He discussed the underrepresentation of these groups in the medical workforce and clinical trials.
- He shared data from lung cancer trials, showing low participation rates of black and Hispanic populations.
- He emphasized the need for more targeted clinical trials to address disparities and improve outcomes for all populations.

Challenges in Lung Cancer Research and Cell Line Diversity

- Dr. Manley discussed the lack of racial and ethnic diversity and gender representation in lung cancer cell lines.
- He highlighted the significant male-to-female ratio in cell lines and the need for more diverse representation.
- He mentioned the importance of using cell lines that reflect the populations with the greatest disparities.
- He emphasized the need for more inclusive and representative research to address health inequities.

Building Trust and Representation in Cancer Communities

- Brad Power and Dr. Manley discussed the challenges of engaging African American men in cancer forums and the importance of representation.
- Rochelle Prosser shared her experience with support groups and the need for trust and representation to build community.
- Dr. Manley and Rochelle Prosser emphasized the importance of intentional outreach and building partnerships with community groups.
- Brian McCloskey asked for recommendations on building trust with underrepresented communities, and Dr. Manley suggested reaching out to advocacy groups and community leaders.

Digital Tools and Access to Information

- Frank Nothaft discussed the importance of digital tools in making information accessible to all, especially in under-resourced settings.

“How Disparities and Workforce Diversity Impact Cancer Patients and Caregivers” (Eugene Manley, PhD) [#111]

- Dr. Manley agreed but highlighted the digital divide and the need for both digital and print resources.
- Rochelle Prosser and Ryan Moon suggested potential contacts for collaboration, including Dr. Kim Rhoads and the Zero Cancer group.
- Tucker introduces Rabble Health, a mobile app to help patients and caregivers navigate the healthcare ecosystem, and discusses its success in Memphis.

Addressing Financial and Access Barriers

- Dr. Manley discussed the financial toxicity of cancer treatment and the need for more affordable options.
- Rochelle Prosser mentioned the National Institute of Health's failed program to pay for patient transportation to screenings.
- Dr. Manley and Rochelle Prosser emphasized the importance of educating providers and improving access to biomarker testing.
- Rebecca Driscoll highlighted the challenges of offering and covering targeted therapies, especially for underserved populations.

Upcoming Summit and Facebook Group

- Dr. Manley shared information about the second Lung Cancer Health Equity Summit in November, which aims to bring together stakeholders to discuss solutions for reducing disparities and improving outcomes for black and Latino patients.
- He mentioned the creation of a Facebook group for black and Latino lung cancer patients and survivors.

“How Disparities and Workforce Diversity Impact Cancer Patients and Caregivers” (Eugene Manley, PhD) [#111]

TRANSCRIPT

Brad Power
This is the Cancer Patient Lab.

We're honored to have Eugene Manley join us. He'll be talking about equity in cancer care and some of the issues that he's been working on in disparities, which is, of course, a well understood issue that got highlighted by the pandemic. Eugene was introduced to us through Rochelle Prosser, who is a super caregiver, both for her family, but also more generally. If you haven't seen or heard of Rochelle, you should check her out and the session we had with her.

This is for information purposes only. This is not medical advice. We try to give information to patients such that they can take it to their medical team and help guide their care.

The Cancer Patient Lab is a patient-led, non-profit, all volunteer organization. We request that people make donations of their time and money, and you can do that through our website.

SCHEQ
EQUITY • OUTCOMES

www.scheq.org

STEMM & Cancer Health Equity Foundation

Eugene Manley, Jr., Ph.D.

Eugene Manley 2:02
I'm Eugene Manley, the founder and CEO of the STEMM and Cancer Health Equity Foundation, or SCHEQ Foundation. I'll have more description about the nonprofit. By training, I'm a mechanical engineer, biomedical engineer, and a cell and molecular biologist. A lot of my work has revolved around musculoskeletal biology, biomechanics and different approaches, and cancer biology, specifically related to lung and breast cancer. I transitioned to the nonprofit space and have worked at the AACR, Lung Cancer Research Foundation, and Lungevity, in roles that have spanned grant administration, fundraising, mentorship and training program

development, health equity, running webinars, and a lot of STEM outreach and community engagement.

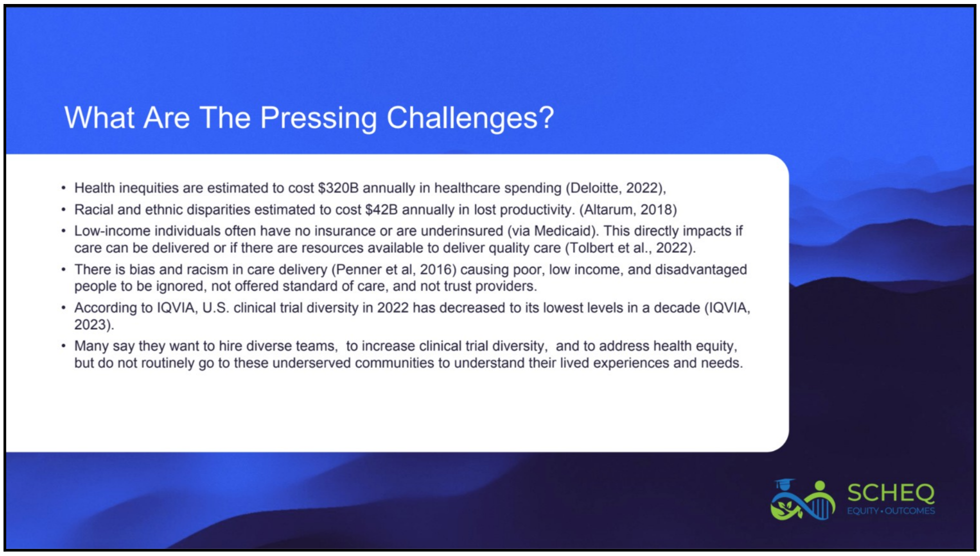
As I went through my career, I saw a lot of challenges for diverse scholars in academic fields. Often there's a lack of diversity as far as representation of the faculty. There's a lack of diversity and leadership, and many people get on these programs that support diverse scholars, but we don't really do a lot to ensure that these diverse scholars are advancing, and many of these scholars, overcoming many things, will get into these academic and medical spaces. We really should be making sure they can excel, because we need them in the workforce to provide that standard of care for these underserved populations.

I launched SCHEQ about a year ago. I should probably make a post about that.

The overarching thing that we're really trying to talk about is that we know health inequities cost about $320 billion annually. We know racial and ethnic disparities cost $42 billion annually in lost productivity. These numbers change depending on the reference and citation that you find. Low income individuals often either have no insurance or are underinsured, and so this impacts the care that can be delivered or the quality of care that they receive. We know there are studies that show there's bias and racism in care delivery, and patients can sense when a physician is going to be biased as soon as they walk in the door. If you think that this translates to trials where many of these trials are run at major medical centers, and the trial teams aren't diverse, the sites aren't diverse, so these diverse patients are civilly those that don't speak English have a lot of troubling places. They just don't feel seen.

We know there have been a lot of discussions about clinical trial diversity, but the acute view report last year showed that trial diversity is at the lowest level it's been in a decade. While we're talking about it, we're still not taking the steps to really go and accurately and actively address it. And while many say they want to have diverse teams, increase trial diversity, and address health equity, they don't really routinely go to these underserved communities to understand their lived experiences.

“How Disparities and Workforce Diversity Impact Cancer Patients and Caregivers” (Eugene Manley, PhD) [#111]

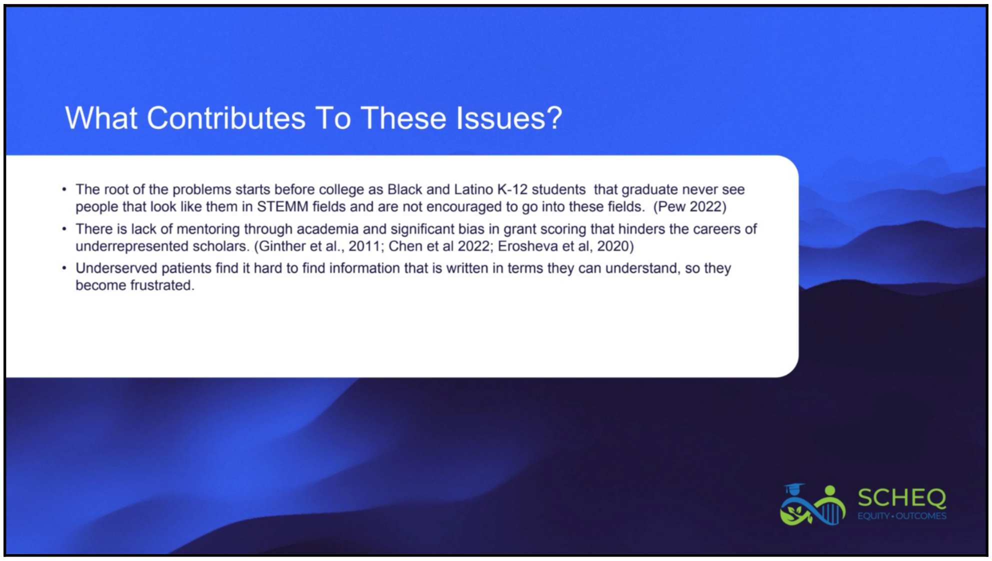


What Are The Pressing Challenges?

- Health inequities are estimated to cost $320B annually in healthcare spending (Deloitte, 2022),
- Racial and ethnic disparities estimated to cost $42B annually in lost productivity. (Altarum, 2018)
- Low-income individuals often have no insurance or are underinsured (via Medicaid). This directly impacts if care can be delivered or if there are resources available to deliver quality care (Tolbert et al., 2022).
- There is bias and racism in care delivery (Penner et al, 2016) causing poor, low income, and disadvantaged people to be ignored, not offered standard of care, and not trust providers.
- According to IQVIA, U.S. clinical trial diversity in 2022 has decreased to its lowest levels in a decade (IQVIA, 2023).
- Many say they want to hire diverse teams, to increase clinical trial diversity, and to address health equity, but do not routinely go to these underserved communities to understand their lived experiences and needs.

SCHEQ
EQUITY • OUTCOMES

There are many, many reasons that contribute to these issues. One is that typically black and hispanic students, before finishing high school, will rarely see people that look like them in STEM fields, or even be exposed to STEM fields. Like I mentioned earlier, there's a lack of mentoring through academia and medicine, and there's a significant bias in grant scoring, whether NIH, NSF, and others. This really impedes or inhibits the careers of these diverse scholars. Looking at it from a patient level, because I grew up poor, and I see it with my family: these poor and underserved patients find it hard to find information that is written in terms they can understand or from their perspective. When they don't see representation, they then engage less with care delivery.



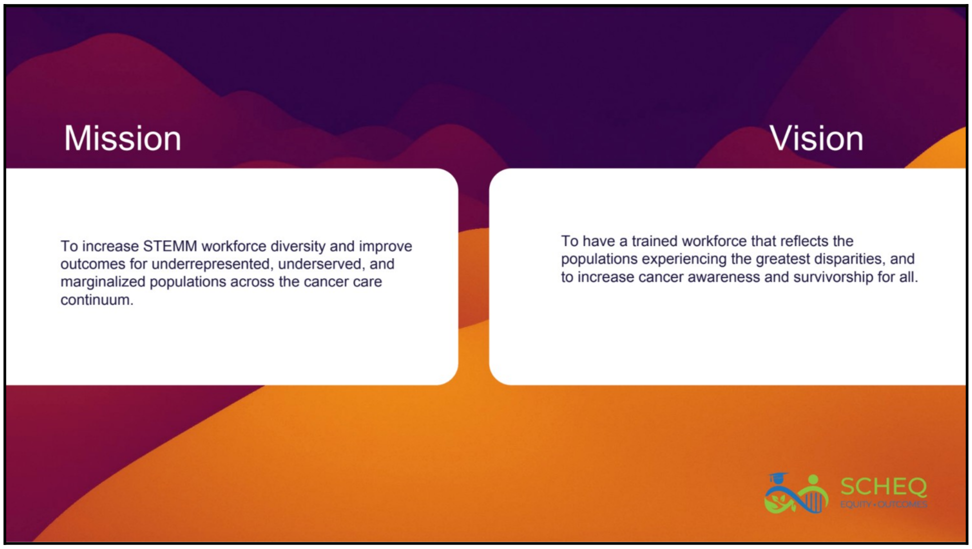
What Contributes To These Issues?

- The root of the problems starts before college as Black and Latino K-12 students that graduate never see people that look like them in STEMM fields and are not encouraged to go into these fields. (Pew 2022)
- There is lack of mentoring through academia and significant bias in grant scoring that hinders the careers of underrepresented scholars. (Ginther et al., 2011; Chen et al 2022; Erosheva et al, 2020)
- Underserved patients find it hard to find information that is written in terms they can understand, so they become frustrated.

SCHEQ
EQUITY • OUTCOMES

The mission of SCHEQ is to increase some workforce diversity and improve outcomes for underrepresented, underserved, and marginalized populations navigating the cancer care continuum. The vision long term is to have a trained workforce that reflects the populations having the greatest disparities, and to have increased cancer awareness and survivorship for all.

At a high level we want to work with diverse scholars from K through 12, all the way through their academic training, to get them exposure, access, help them understand how to navigate degrees, degree transitions, and how to deal with racism and bias. It puts them in a position so they can excel in whatever career they choose. The other objective is to improve outcomes from these underserved populations by providing information and resources, and then lastly, to enhance or improve research that impacts these populations.



Mission

To increase STEMM workforce diversity and improve outcomes for underrepresented, underserved, and marginalized populations across the cancer care continuum.

Vision

To have a trained workforce that reflects the populations experiencing the greatest disparities, and to increase cancer awareness and survivorship for all.

Goals

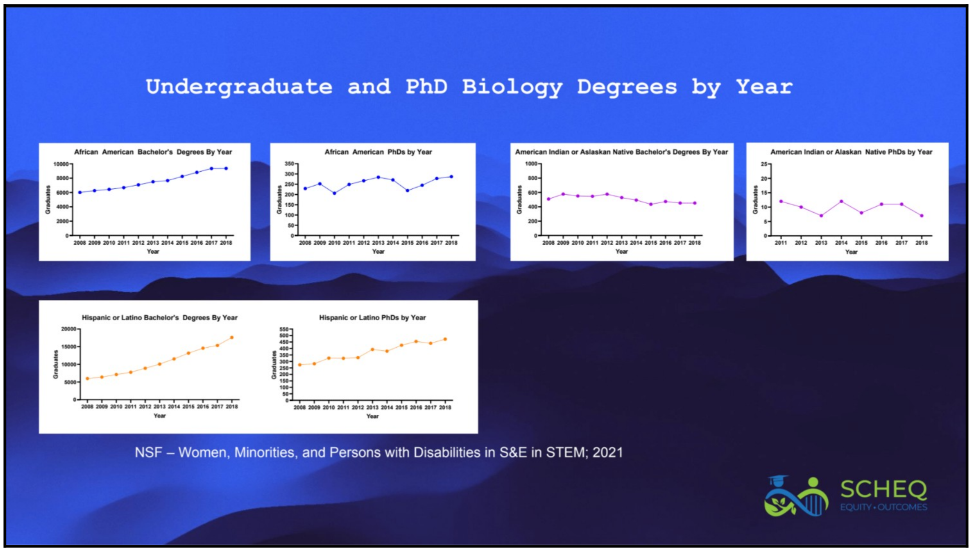
Objective 1 – To increase exposure (K-12), opportunities, mentoring, training and workforce diversity in STEMM at all levels.

Objective 2 – To improve outcomes for underrepresented, underserved, marginalized, and invisible patients across the cancer care continuum.

Objective 3 – To enhance or improve research for underserved and minoritized groups.

Some people say that there is a STEM, leaky pipeline, but really what I wanted to pull out was this data from the NSF [see screenshot below]. The left side of each of those panels shows biology degrees, Bachelor degrees, by African Americans at the top left; Hispanic or Latino at the bottom left; and then the third column for American Indian, Alaskan native. The right side shows PhDs and biology by year. What you really see is that we still really have little representation of American Indian or Alaskan native. While we have more African Americans finishing with biology degrees, they're not really advancing to PhDs or they're not finishing. There's many challenges in place, and with Hispanics, they are at least increasing in their PhDs, but they're still significantly underrepresented relative to the US census population. This also applies in the medical workforce.

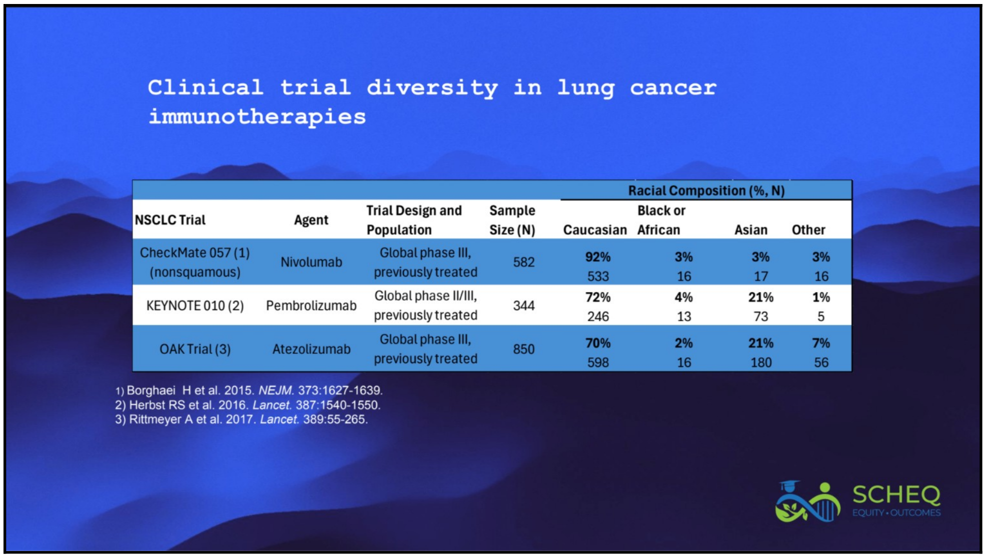
As we talk about patients and clinical trial diversity, I pulled out some data from a report that maybe came out a couple years ago. These are just three lung cancer trials for immunotherapies. I wanted to show you that they have their patient populations. The top number on the right is the percent that group represents. The bottom number is the total number of people in that trial. What you'll see for those three trials–these are FDA approved therapies, specifically in lung cancer–is that we had no more than 4% participation of Black but overall, about 3%. We had little representation of Asian populations. Depending on the study, there is a quarter of 5% participation of Hispanic populations in these trials. These trials are still getting past phase three, they're going to the post market, and then you're seeing different adverse events. We see differences in black populations as far as epigenetic markers, biomarkers admixture, and immune marker expression. We can't just keep running trials on the majority and then think we're going to get a solution for everyone. We have to really be more focused and targeted as we do these trials.



Undergraduate and PhD Biology Degrees by Year

NSF – Women, Minorities, and Persons with Disabilities in S&E in STEM; 2021

“How Disparities and Workforce Diversity Impact Cancer Patients and Caregivers” (Eugene Manley, PhD) [#111]



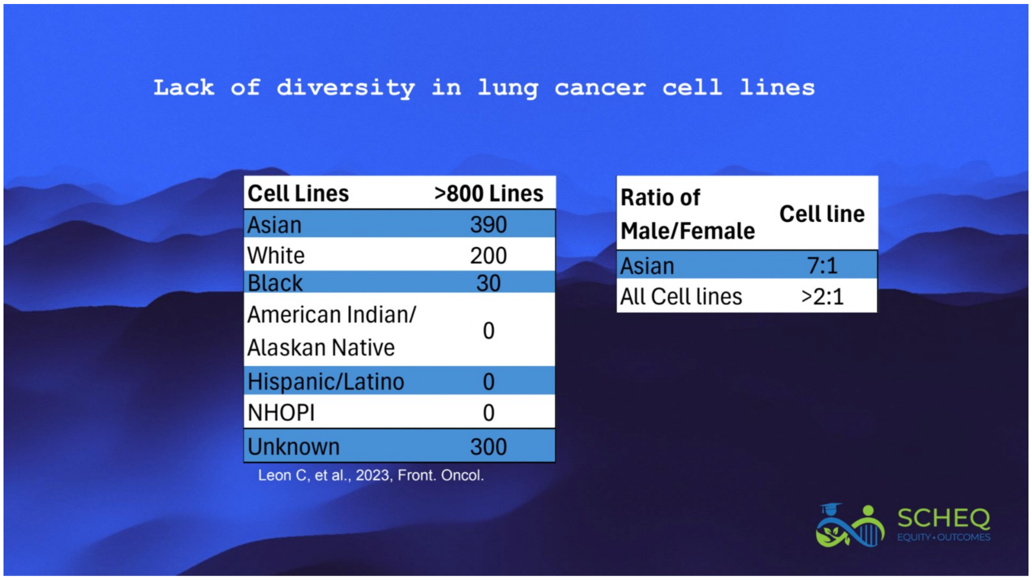
Clinical trial diversity in lung cancer immunotherapies

NSCLC Trial	Agent	Trial Design and Population	Sample Size (N)	Racial Composition (%, N) Caucasian	Black or African	Asian	Other
CheckMate 057 (1) (nonsquamous)	Nivolumab	Global phase III, previously treated	582	**92%** 533	**3%** 16	**3%** 17	**3%** 16
KEYNOTE 010 (2)	Pembrolizumab	Global phase II/III, previously treated	344	**72%** 246	**4%** 13	**21%** 73	**1%** 5
OAK Trial (3)	Atezolizumab	Global phase III, previously treated	850	**70%** 598	**2%** 16	**21%** 180	**7%** 56

1) Borghaei H et al. 2015. *NEJM.* 373:1627-1639.
2) Herbst RS et al. 2016. *Lancet.* 387:1540-1550.
3) Rittmeyer A et al. 2017. *Lancet.* 389:55-265.

This was a study we just published last year with some collaborators from USC and Florida A & M [see screenshot below]. We performed a review of all the lung cancer cell lines that were out in the literature. We found over 800 cell lines. We found many duplicates, and what we found was of these cell lines–this is across the whole set of lung cancer–we found 390 cell lines from Asian, 200 from white, 30 from black, and 300 from unknown. None were from American Indian, Alaska, native Hispanic or Latino, Native Hawaiian or Pacific, or other Pacific Islander. That means that all our trials and therapies in lung cancer are still based often on TCGA and GWAS studies, which still are over-represented for European populations, and they don't have representation of the populations that tend to have the greatest disparities. We're still going to continue to exacerbate the problems in trials, because we don't even have starting material that reflects these populations. The other important thing we really wanted to point out is that when we looked at the ratio of male to female cell lines and the Asian subset, we found the ratio of male to female cell lines was seven to one. Then across all the cell lines, in general, the ratio was greater than two to one, male to female. We have a significant lack of both racial/ethnic diversity and gender representation in lung cancer cell lines.

“How Disparities and Workforce Diversity Impact Cancer Patients and Caregivers” (Eugene Manley, PhD) [#111]



Lack of diversity in lung cancer cell lines

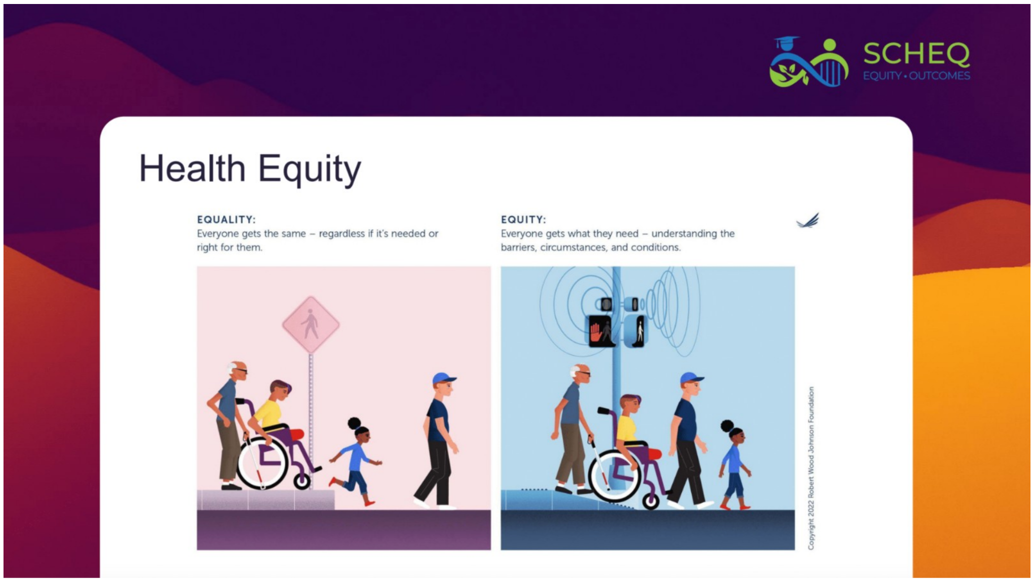
Cell Lines	**>800 Lines**
Asian	390
White	200
Black	30
American Indian/ Alaskan Native	0
Hispanic/Latino	0
NHOPI	0
Unknown	300

Leon C, et al., 2023, Front. Oncol.

Ratio of Male/Female	**Cell line**
Asian	7:1
All Cell lines	>2:1

SCHEQ
EQUITY • OUTCOMES

This is a description by Robert Wood Johnson that talks about the difference between equality and equity. Equality says everyone can get the same thing, but it doesn't mean you need the same thing, but equity means you are creating specific interventions for a person or a group based on what they actually need so that they can have the same access as everyone else.



SCHEQ
EQUITY • OUTCOMES

Health Equity

EQUALITY:
Everyone gets the same – regardless if it's needed or right for them.

EQUITY:
Everyone gets what they need – understanding the barriers, circumstances, and conditions.

Copyright 2022 Robert Wood Johnson Foundation

“How Disparities and Workforce Diversity Impact Cancer Patients and Caregivers” (Eugene Manley, PhD) [#111]

This is my contact info.

SCHEQ
EQUITY • OUTCOMES

www.scheq.org

Thank You

Eugene Manley, Jr., Ph.D.
emanley@scheq.org

Brad Power 14:35
We started out as the Prostate Cancer Lab, and prostate cancer disproportionately affects African-American men. You can look around. There are no African-American men in the audience. I may be wrong, but there are two hypotheses that have been floated on that. One is that African-American men don't talk that much about their care. Rochelle talked about that with her husband. There's a “macho” thing where you don't talk about having cancer, and therefore you don't come to a forum where you're learning about cancer, because you're keeping it internal. If we want to engage all people, and particularly in prostate cancer, where do you think we have services to offer? The other thing is that if an African American man like yourself joined a session, and you look at the people here and you don't see any African American men, you might say, “Well, this isn't for me.” There's also the question of “how do you break through and get representation?” I'm just personalizing the issues that we're facing, to see if you have any views or thoughts on what we could or should be doing that we aren't.

Eugene Manley 16:10
You raised two very good points. As you said, African Americans tend to not want to talk about their conditions or diseases partly because one, it's “macho,” and two, because people don't want to talk about prostate health. But this happens also in breast cancer and many other diseases that impact black communities heavily. We're not really good at talking about our medical history, even to our families. As a result, you weren’t aware of what risk factors you had, because you didn't know other people died of a certain disease, so it's really hard. Part of it is that they might not want to talk about it–maybe there's fear, maybe there's stigma. They might not want to bother other people. Society, at least in the US, contains so much already structural,

systemic racism built in what we deal with every day. “The healthcare system is not going to listen to us. Why should we bother even more?” That started to bring in some thoughts of fatalism.

As far as your other point [about not feeling represented at sessions and forums], that's also a valid point, too, and this happens at many other nonprofits. They'll have events for patients, and sometimes minority patients–Black or Hispanic–will join a meetup or group, but often will not see anyone that looks like them. That can be offsetting, because then it's like, “Am I going to find any community here?” Another thing is, because the population tends to be more European and they tend to have better access to care and resources, these patients will say, “my doctor recommended this, my doctor recommended that.” The minority patients are often never offered any of these things, so they still feel left out and isolated. It's hard to bridge that gap. You would have to consciously think about having representations at every level, but then also try to build partnerships and relationships with the groups that are working with these communities to welcome them in. A lot of it is trust and trustworthiness.

Brad Power 18:30
Rochelle, do you want to chime in with something to add there?

Rochelle Prosser 18:43
Yes, Eugene raises a very valid point that we do see, and I have been working with certain support groups over the years as I was going through my journey with my family. When we first started, there wasn't anyone that looked like me, let's just be honest. But that was where the resources were. To Eugene's point: when a community is not being offered the latest and greatest technology, it becomes off-putting and makes them say “Should I even be here? Is this right for me?” We have to build trust and bridges at some point. Sometimes, the first has to be that representation to bring the rest of the boats as, when one ship rises, so does everyone else. Specifically to your question, Brad, about breaking the mold or breaking that glass that is preventing true socialization: it takes an intentional outreach. When you're putting these sessions on, you want to address a certain community. You want to go ahead, be intentional, and make sure that you bring those speakers in, even knowing that the representation is not going to be there in the audience. But it will come the more that you invite.

Brad Power 20:08
That was going to be my next question. You've essentially got a chicken and the egg problem– there's nobody there, so how do you break that barrier to get some people to show up? What I heard from you is to continue to invite and show your openness. To get some people to show and then, from there, you can build from that base.

Rochelle Prosser 20:28
That's correct.

Brian McCloskey 20:37

I know the Prostate Cancer Foundation (PCF), for example, has a lot of initiatives in this space, but who would you recommend that we kind of build these bridges to create this trust so that we can bring in underrepresented communities?

Eugene Manley 21:00
Cancer is not my specialty, but I do know that Charles Rogers is part of this black prostate cancer collaborative. He does a lot of work with advocacy, health equity, and bringing education and resources to black patients with prostate cancer. I just can't quite remember the name of the collaborative off the top of my head.

Brian McCloskey 21:27
It doesn't necessarily have to be prostate cancer, so it could be brain, pancreatic, or potentially broader than that as well. I'm just trying to figure out, like, how to create that bridge because this has been sort of an enigma for us.

Eugene Manley 21:44
There's so many disparities across cancer, and those underserved populations often don't even know the resources exist. How do they feel when they're engaged in a healthcare system? Like I said earlier, if you go to a major medical center, the staff mostly is not diverse. If there's a certain behavior they have towards you when you don't look like you have money, you feel beaten down over and over and over. It's just going to take some intentionality, time, and even digging to find out where minority patients are to present and talk to them as well as understand their needs. You can say “I have all these resources,” but if they don't know you at all, they are not going to come and trust you.

Brad Power 22:33
Eugene, there's a lot of common ground, actually, in what you're saying. Everybody here is a strong advocate for themselves, as Rochelle was, and, in general, for improving the system. So it's both “Make things better for me” and “Make the system better.” Everybody here is that. And so everybody's fighting the system, not with the same issues or the same intensity as people of color, but nevertheless, there's actually a lot of common ground in that. In the session we had the week before last with Ari Akerstein, he calls himself “the rogue patient,” and his idea is that he goes in with a fair amount of skepticism. His pathologist gave him a diagnosis, and as he was getting second opinions, one of the people he asked questioned whether that pathologist made a right diagnosis. He then tracks that down and eventually determines that the initial diagnosis was flawed. So he’s going to the medical system, not sure that it's there to serve him as though he can just embrace it as something that’s going to do the right thing for him.

That's one attitude, and there are many stories. One of my favorite ones is Brian's story of lining everything out so that he could get a tissue sample and it would be sent off for analysis, and it got stuck in the internal pathology lab at UC San Diego. We have a lot of stories of breakdowns in the system. We share those breakdowns. There's a lot of common ground I think that we could jointly embrace, if we present that message.

Eugene Manley 24:27
That was a strong set of patient advocates, but if they don't know how to do advocacy or want to be better advocates, I think Rohan Jeremiah at the University of Illinois Cancer Center in Chicago does programs on citizen scientists, so they really go into the communities and teach community members how to be advocates for their community. I think IASLC, the International Association for the Study of Lung Cancer, has an advocacy training program. I think even the AACR (American Association for Cancer Research) has one as well.

Frank Nothaft 25:20
Thank you for having me. Just my quick way of introduction, my background is in the genomic diagnostic space and oncology, and I'm currently working on a digital health tool to help patients understand their care choices and navigate. I think one of the big undercurrents that I've been thinking about the last few years is time toxicity and financial toxicity, which are major problems across all of cancer. They're particularly high impact in groups that are socioeconomically and racially disadvantaged. I know you had mentioned in your abstract that you've been doing work in how you can use digital techniques to help patients with learning and understanding their options. Would you be able to share some of your learnings from that work and where your focus is right now?

Eugene Manley 26:28
We're doing it because I have a long track record of doing research and advocacy. We just launched a nonprofit, so we're in the process of building out our online resources, and then, with those resources, we're going to go to different communities that need them. We are then going to work backwards to build the community, because if the patients don't know you have it, then how will they have you? We have to create it first and then go out. We are still in the building stage, which I know probably does not answer your question, but we do have a network that can get information out, so we are leveraging that.

Frank Nothaft 27:08
That's super helpful to hear. I'll follow up with you offline. You actually led into one of the curiosities that I had, because I've seen public health efforts outside of the US in under resourced settings that have taken a similar approach where you're “bootstrapping” with content, working closely with the community to make the content work for the community, and iterating back and forth, so that makes a ton of sense. Thanks for elaborating.

Brad Power 27:43
If I could represent what Frank's saying, I think the point is if you have digital tools, everyone has equal access. One of the problems you had mentioned is that, when you show up at a session, facility, or wherever it is, you don't see people that look like you–that's not an issue when you're online. If somebody wants to pursue information and figure out what to do, those digital assets provide “equal opportunity” information. It’s leveling the playing field, at least for that set of issues. Of course, there are other issues, but at least for that set of issues, digital tools would seem to be a way to look things up on your own time and not necessarily have to tell everyone and go through the social barriers.

Eugene Manley 28:43
However, we still will continue to have a digital divide, because we still don't have everyone with broadband access, as many can't afford it. You're essentially using the digital tools as a conduit to bring information out to people. Then, you can have printed stuff which you can take to community events and fairs; you’re still getting the information out that way. Since we're launching and starting, we have to create what I can do first, which is content, and then leverage the network. You're pinging off these things, but you don't want to just solely do digital because you will still miss people, and that's, sadly, what we're doing in society. We have a digital app, but we still have people that don't have access to phones and can't afford Internet, and some of them are in very rural areas where WiFi is inaccessible.

Brad Power 29:33
In the chat, a couple of folks have suggested contacts we might reach out to to get the ball rolling.

Ryan Moon 29:54
Sure. Dr. Kim Rhoads–she used to be a neurosurgeon at UCSF, and then she moved to outreach and diversity and equity–she's officially the Director of the Office of Community Engagement at UCSF, and she runs these quarterly meetings. They call them “cab to chat and choose,” and it's like a discussion, almost similar to this one in some ways, where they bring speakers and have little chats. They're actually majority African American attended. I think that could be a good group to perhaps reach out to as maybe a way to collaborate with or join together forces in some way. I'll send a description of the meeting. This is a meeting from a while ago, but it has a good description about who Kim Rhoads is.

Brad Power 31:10
Thanks. We'll include the chat in the notes.

Rochelle Prosser 31:19
Cancer Consortium, in the broader sense, looks generally at cancers, specifically pancreatic cancers, more rarer diseases, or ones more difficult to treat, and they're affiliated with the NIH. You could try there. Also, getting down to where people are, there is ZERO Cancer. Their motto is “The end of prostate cancer.” One person I’d like to mention is Chris Bennett, and she works with another group that is called the Black Men's Prostate Cancer Group in New Jersey. I would like to invite them to meet you, Brad, at least, to get the ball rolling. They are close in your immediate area, or the New Jersey area, for those that are on the call, and then we can provide some diversity and start putting the olive branches out to different advocacy groups. There's another group that is run by Global Alliance, and this is the Male Breast Cancer Group. It is led by Cheri Ambrose, and she has a ton of diverse men here. Yes, men get breast cancer too. As an aside, it stems from prostate cancer, so you might want to reach out to them as well. I believe she's up in the New York area.

Brad Power 33:13

Tucker, if you don't mind my putting you on the spot, I don't think most people here know about the work with Rabble Health, working with disadvantaged communities and trying to bring guidance, in particular, some of your software to help people with their cancer care.

Would you mind introducing what you do with Rabble Health and how you've bridged to that?

Tucker Herbert 33:42
Rabble Health is a mobile app to empower patients and caregivers to navigate the healthcare ecosystem. When we look at the landscape from a broad perspective, insurance companies and healthcare systems are increasingly using technology to, as they put it, standardize care. But in some cases, the act of standardizing care means that there's a lack of personalization, and it can mean that patients are treated in a way that doesn't account for their racial and ethnic background, or is personalized to what is ideal for them. Our proof of concept was deployed in Memphis focused on the Black breast cancer population, and there it was to help increase access to services so that patients could reduce those disparities in care and outcomes that they were having. We've published on that in a couple journals and conferences, so certainly feel free to reach out to or ask questions, if any more detail would be helpful.

Brad Power 35:04
In terms of full disclosure, I should mention that I'm an advisor to Rabble Health and that Aubrey Kelly, founder of Rabble Health, is going to be joining our accelerator.

Rabble Health’s proof of concept became the model for a very clever hack of the medical system, which is trying to bring those resources to disadvantaged groups and leveraging pharma to fund it as some of the work that they would do to thereby access broader communities in their clinical trials. Could you speak to that sort of expansion, from that success in Memphis to that broader business model you've been developing?

Tucker Herbert 36:01
We found that in a lot of cases, there is really strong alignment between the goals of biopharmaceuticals and goals of patient advocacy groups, particularly where it's about improving access to the most innovative treatments that are the most effective. We look for those specific opportunities where there's that overlap in that Venn diagram, and we work to drive change, typically funded by biopharma. In some cases, we're getting funding from insurance plans, public health, and even hospitals.

As a follow on to that project that we did in Memphis, we're having discussions to get earlier in the journey to reduce disparities in screening rates. Cancer screening rates haven't recovered, particularly in breast cancer, post pandemic to what they were as a lot of patients avoided that treatment while they were under the pandemic.

Eugene Manley 37:30
We published a paper a couple years ago that talked about how Covid-19 has disrupted lung cancer clinical trials, and we made some suggestions about what FDA and trials could imply

from the lessons we learned. It was more about remote monitoring, letting patients go to facilities closer to where they live to just get routine blood work, and trying to do more televisits when possible. We talked about reimbursing, but the biggest challenge for patients on trials is that they still have to take time out of work, and are you still giving them housing? What are you doing now to help them navigate that? What about their families? We are concerned that we'll start seeing an uptick in lung cancer cases because we missed two plus years of screening because things got canceled and moved left and right. You didn’t even know if you could go in.

I think someone else had a comment about the three hundred ninety Asian versus two hundred White cell lines. Those were not mainly sourced in China. Some of those were Chinese, Japanese, Korean–they were from all over. Of the ones that were from Black patients, I think fourteen or fifteen of the thirty cell lines had a mixture between forty-one and seventy-five percent, which is not surprising because of the slave trade and forced migration, so you had to change the genetic backgrounds. But I think that stuff is off. We're going to see, unfortunately, some more increased cancer rates just due to Covid-19 disrupting trials and screening in general.

Rochelle Prosser 39:27
The National Institutes of Health adopted a program to pay for the transportation and the coordination of getting patients to be screened recently. They released the results of that, and they didn't explain the reasons. They just said it wasn't a viable solution. The cost outweighed the actual benefit of paying for screening.They didn't say what those costs were, what the issues or the hangups were that prevented patients from going, or what the cost overruns were, whether it was parking, transportation, airline, etc. I ask in terms of lung cancer and breast cancer: from what you know on the academia side, what do you feel, within the communities that you are closest to, are some of the issues that may not have been addressed by the National Institute of Health?

Eugene Manley 40:39
More local efforts educating the providers. As far as we've seen, like City of Hope and a couple other studies have done, where if the surgeons have gone and trained primary care providers about the updated lung cancer screening guidelines, they've been able to see sometimes a twenty to fifty percent increase in uptake of lung cancer screening. It's often still that we don't have primary care providers that know about screening and the new guidelines. We still have some physicians that have been around from days before EGFR was discovered, so patients may still get offered only chemo and radiation and may not even get offered biomarker testing or NGS testing. Even when they do get this offer, you may only get one to three biomarkers tested if you're lucky and not the ten or eleven that are available. If you don't get all your biomarkers tested, you're highly likely to miss on treatments that could possibly extend your life and maybe have some curative impact for you.

Rochelle Prosser 42:01
About the biomarkers, that would be a barrier for certain communities where they have a limitation on what the serum analysis or the lab assay would be. That would be a barrier, not

knowing that it's actually ten biomarkers you're supposed to look for, rather than the standard two to four.

Frank Nothaft 42:37
I just wanted to riff on that point. It's a really important one. It's actually a particularly big challenge in prostate cancer. We screen about ten percent of patients for genomic biomarkers in prostate cancer, and actually we miss about twenty percent of patients with metastatic prostate cancer, who do not wind up receiving any systemic treatment after diagnosis. It’s a problem that's particularly prevalent in the minority population. It's a major problem across all cancers. There’s a lot of evidence in lung and prostate cancer indicating that it’s a big problem. It's a big issue from an equity and access perspective.

Brad Power 43:32
Chris Apfel, what are you seeing in your experience regarding minority access to testing?

Chris Apfel 43:51
I have the impression that the challenge is that minorities are often less involved and less informed about the different options, and because of their socioeconomic situations, they usually don't have the resources and the knowledge and information about what’s all out there. It's reflected in our setup. The primary issue is access to information and being aware of it. Physicians, often, as you know, may not even refer patients to all the options there are. There is an interesting website and book from Dr. Archelle Georgiou, who also has a podcast called “Speak Up for Your Health.” Her book is called “Healthcare Choices.” She is also a patient advocate.

Often, patients are not aware of what's out there, and physicians usually don't provide the spectrum of choices that are out there, even within the standard of care. What we do is that we go beyond the standard of care. In terms of racial disparities, I think that's where it starts. Patients are often not offered those different options.

Brad Power 45:29
Rebecca Driscoll has a long background in diagnostics, having worked at Foundation Medicine back in the day, and now is with Cancer Help Desk.

Rebecca Driscoll 45:44
I'll echo what Dr. Apfel just said: patients aren't offered options. We see this clearly across the board, but obviously in certain demographics and ethnicities. But the other thing that we hear, in speaking with physicians about this, is whether or not they're going to treat them with a targeted therapy. There's this issue around offering biomarker testing, but then there's this idea of, “I'm not going to treat with a targeted therapy.” Or, “Your insurance isn't going to cover the targeted therapy that might cost $30,000 per pill.” This is a huge dilemma. I think it goes beyond just not offering the testing; it is to the actual therapeutic options that they're going to cover for that patient. We're not just seeing this in the underserved. We're seeing it across the board in that decision-making process in the clinical setting.

Eugene Manley 46:50
Medicine cost is one of the leading causes of financial toxicity, and also part of the reason a lot of people don't even get therapies. Within usually a year of a cancer diagnosis, most patients have gone bankrupt or lost their homes and cars because they just can't afford the treatments. It takes so much out of you that you can't go to work at all. It's this whole bunch of things that just compound each other.

Brad Power 47:27
There's a comment in the chat from Allen Morris about molecular biology and so on: have you ever pondered why sarcomas, the malignancy of the musculoskeletal system, are so rare, considering that their cell line of origin is already inherent in movement capability. Do you have any quick thoughts on that?

Eugene Manley 48:18
Sarcomas are typically soft tissue diseases. So they can be hard sarcomas, they can be muscle, they can be connective tissue. Now, there are also osteosarcomas and bone which are bone cancers. If my memory is correct, osteosarcomas tend to affect children more than other populations, but these are harder to diagnose and study because they don't manifest as most other cancers do, so they're always hard to find and treat, especially the soft tissue sarcomas. But, since that's not my specialty, I cannot speculate much more on the topic and sound unintelligent, so I shall not.

Brad Power 49:09
Rochelle added a comment saying there's a higher prevalence in Hispanic communities and in Latin America for those cancers.

Rochelle Prosser 49:16
Yes, there is. Hispanic communities, Latin America, South America, Armenia, and the Middle East are where you see a lot of those.

Brad Power 49:31
Eugene, anything you want to leave us with? Any final thoughts?

Eugene Manley 49:38
I want to say thank you for inviting me to speak. I hope it was very informative for all of your patients. Here, I try to sort of overlay what I've done in my career and how I've gotten to this point. Someone asked, “how do you find patients?” One other thing we are doing in November is our second Lung Cancer Health Equity Summit. The theme of this event is “Black and Latino Patients Navigating Lung Cancer: Stepping Stones to Equity.” Because of my work in lung cancer, I saw a massive lack of information going to Black and Hispanic populations to help them understand just what their treatment options are, how to engage in care, how to get screened, and how to advocate for second opinions. So, we decided to put together our second summit which is really bringing together stakeholders, from patients, researchers, and nurses

that are presenting solutions that they've created that are reducing disparities and inequities and/or improving outcomes. We always talk about the problems, but do we ever bring together people that are creating the solutions? That's what our summit is focused on. We have the flyer up on my LinkedIn page. If people want to register, it's tinyurl.com/lches. That was my little plug. It's really going to help bring more awareness to these patient populations, and we're going to keep building it up.

Brad Power 51:07
I know that you and I talked about this before, but one of the things we believe about the Cancer Patient Lab is that we can find role models of patients who are, let's say, in this case, Black or Hispanic, who have succeeded in navigating. If you engage and if you're an advocate for yourself, you'll get better outcomes. There is a role model that holds that out for others to follow. Have you found those role models in your travels and are the people you would be bringing to your conference fit that profile?

Eugene Manley 51:36
Yes, ironically, one Latina patient reached out to me a month ago and said, “Are there any meetup groups for Black and Latino patients with lung cancer?” I said, “To my knowledge, no.” She beat me to it. She said, “Oh, well,” and created a Facebook group called “Shades of Color,” literally for Black and Latino lung cancer patients and survivors. Now they've added me to the group, so I am starting to interact with the community that is going to be beneficial and critical as I grow what I’m doing. It happened to be the right time that we had a conversation.

Brad Power 52:13
We'd be interested to learn more as you evolve, and we hope we can help you in your upcoming conference.