Transcript: ELSI Friday Rorum

Addressing Racism in Research and Clinical Practice

Friday, December 11, 2020

>> Mildred Cho: For those of you who are just joining us, I'm just going to wait a few minutes to let people enter the Zoom. And this is being recorded, just so you know. Okay. I think we are live streaming now. So I will welcome you to the ELSI Friday Forum series. This is our second one of the year, and the second one ever. I'm Mildred Cho from the Stanford Center for Biomedical Ethics, and we will be discussing addressing racism in research and clinical practice today.

For those who are new to the forum, it's hosted by the Center for ELSI Resources Analysis held on the second Friday of every month for an hour starting at noon Eastern Time. And we also have a Zoom room reserved for more informal discussions immediately after the panel for 30 minutes.

For those of you who might be new to CERA, it's a multidisciplinary, multi‑institutional center that provides resources to support research on the ethical, legal, and social implications on genomics and genetics, known as ELSI, and serves to connect scholars, scientists, policymakers, journalists, members of the public, and others to engage in ELSI issues.

It's funded by the National Human Genome Research Institute, NIH, and is managed by teams at Stanford, Columbia University in partnership with the Hastings Center and Harvard University.

CERA's online platform, ELSIhub.org, launched last month, and I encourage to you access resources there including the recording and transcript of this forum, associated reference materials that will be posted in the chat throughout, as well as ELSI literature research instruments, a scholar directory, news and events and much more.

Please also go to the website to sign up for newsletters and events like this one at ELSIhub.org, And also to get daily updates and news on Twitter.

So in terms of participating in the forum today, if you wish to use closed captioning, please turn on the CC button at the bottom of your screen. The panelists' presentations will be relatively brief. So we hope to use the bulk actually, a significant portion of our time in discussion. So please, throughout the panelists' presentations, use the Q&A button which you will find at the bottom of your screen to write any questions for the panelists.

You can register your enthusiasm for a question and elevate it up the list by using the upvote button in the Q&A box. The chat box is available for further engagement and where we will be posting links to resources referenced in today's discussion. But I will be looking to the Q&A for your questions.

So let's turn to today's topic: Addressing racism in research and clinical practice. At last month's Friday forum, we had a spirited discussion about structural racism in genomics lead by Dean Dayna Bowen Matthew and Vence Bonham. And together they lay out a groundwork to help us discuss the issue raised in the NHGRI strategic plan that was released in October of this year which said that genomics, like other scientific fields, must reckon with systematic injustices and biases fully mindful of their importance for health equity.

Our aim today is to discuss what this really would mean in the actual practice of genomic research and clinical genetics. So today we are fortunate to have three panelists who have thought deeply but also specifically about how genomes researchers, clinicians, and ELSI scholars can take action to prevent racism and its harmful effects in their work.

Our first panelist will be Rhea Boyd who is a pediatrician and director of strategy and equity of the California Children's Trust. She has a BA in Africana studies and health from the University of Notre Dame, an MD from Vanderbilt, completed her pediatric residency at USCF and an MPH from Harvard School of Public Health. She's a public health advocate who writes and teaches about the relationship between structural racism, inequity, and health.

You might know her as the author of a health affairs blog post entitled "On Racism: A New Standard for Publishing on Racial Health Inequities," which has been widely read and discussed.

Our second panelist will be Robert Steiner, a professor at the University of Wisconsin School of Medicine and Public Health in Madison, a medical geneticist at the Marshfield Medical Center and chief medical officer of prevention genetics. Even with all those hats, though, you may know him as the editor in chief of Genetics in Medicine the Journal of the American College of Medical Genetics.

Our third panelist is Daphne Martschenko, a postdoctoral fellow at the Stanford Center for Biomedical Ethics. She has a Ph.D. in education from the University of Cambridge and her work advocates for and facilitates cross‑disciplinary research efforts that promote socially responsible communication of social science genomics research findings.

So we will take questions at the end of the third presentation. So I encourage you throughout the presentations to write your questions in the Q&A box, and I promise to get to as many of those as we can for discussion later. So with that, we will turn to Rhea Boyd who will be doing her presentation.

>> Rhea Boyd: Hey, everyone. Thank you so much for having me today. I'm just going to share my slides. Hold on one sec. So today before we begin our conversation, I'm just going to frame out the connections between racism and health. And I think to just say it most simply we have to begin here, right.

Racism kills people. Now, I'm a pediatrician, and I want people to understand that racism even kills babies. This is a study that was just published a couple of months ago in the Proceedings of the National Academies of Sciences that looked at 1.8 million hospital births in Florida. What they found is that when Black infants are cared for by Black physicians, their infant mortality is lower. And they are able to cut their infant mortality gap between Black infants and white infants by half when they are cared for by Black physicians, which is called racial concordance when you match race between patient and physician.

Notably those effects manifest most strongly in babies that were the sickest and in hospitals that delivered more Black infants, which suggests that racial segregation might underpin some of these findings.

We also know that racism kills healthy children. This is also a study from just a few months ago this year in Pediatrics that looked at 172,000 apparently healthy children and their post‑op outcomes. What they found is that African‑American children had more than three times the odds of dying. These are previously healthy children, who had more than three times the odds of dying within 30 days of surgery and a greater relative odds of developing post‑op complications and serious adverse events.

This study doesn't allow us to ask similar questions about segregation because the database that the authors used doesn't include the specific hospitals where children were at. But again we want to ask similar questions about what drives that inequity? What's the mechanism by which racism is killing African‑American children more than other children after surgery?

And as we know, racism kills adults. This is a schematic I have been using during the pandemic to explain that. So when we talk about who has increased risk for complications or early death from COVID, we typically frame that around who has chronic underlying illness, things like asthma or heart disease.

But when we do that, we fail to acknowledge the ways that segregation has profoundly shaped the racial distribution of heart disease in this country or the ways that discrimination increases rates of hypertension and communities of color and particularly for Black Americans, or the ways that environmental racism determines who breathes in clean air and who breathes in toxins, and thus who has higher rates of asthma; or how the racial wealth gap profoundly concentrates poverty within communities of color; or how exposures to toxic stress particularly those that separate children from their caregivers during those early profound periods of development can actually raise one's allostatic load over their lifetime which means the wear and tear on their organ systems and prematurely weather their cells which means prematurely age them such that an individual's chronological age could actually be lower than your cellular age, or said the opposite way, an individual's cellular age could be advanced of chronological age.

And you suffer complications at much earlier ages than expected which is what we have seen for mortality for communities of color during the pandemic. These are all examples of how structural racism has profoundly shaped the racial distribution of COVID, COVID mortality and COVID complications. And it does that because humans use structural racism to offer different humans opportunities, access to goods, services and opportunities via race.

This is how as Camara Jones said who is one of my favorite pediatricians inherited disadvantages, not just inherited disease, has shaped this pandemic. And it also illustrates how the environment the physical but also the structural, the legal, the policy environment in which we are all growing, learning, working, and playing shapes not only our health but the health of our children and our children's children.

So this illustrates how racism then is a devastating root of chronic undertreated disease as we've seen with rates of chronic illness in this country among communities of color, but then also completely preventable premature death as we have seen so devastatingly throughout this pandemic.

So when we ask what's the relationship between structural racism and our bodies, I think we have to turn to the words of author and journalist Ta‑Nehisi Coates who wrote "Between the World and Me," that all our phrasing, race relations, racial chasm, racial justice, racial profiling, white privilege, even white supremacy, serves to obscure that racism is a visceral experience, that it dislodges brains, blocks airways, rips muscle, extracts organs, cracks bones, breaks teeth. We must never look away from this. We must always remember that the sociology, the history, the economics, the graphs, the charts, the regressions all land with great violence upon the body."

That violence could be the violence of policing. As the National Academy of Sciences told us last year, one in one thousand Black men and boys will be killed by police in their lifetime. It could also be the violence of inaccessible healthcare. As we know, communities of color lack equal access to health insurance in this country, which also is a barrier to their equal access to care.

So to adequately respond at scale to racism as the public health crisis that it absolutely is in this nation, we have to be able to name racism, identify how it works, and then work to eliminate it. When it comes to naming racism, we as a field are doing a poor job. This is a systematic review by Rachel Hardeman and colleagues who looked for a decade, 2002 to 2015, and found only 25 articles that actually named institutionalized racism in the article or abstracts. And this is looking at the fifty highest impact journals.

And what's more notable is institutionalized racism was only a core concept in 16 of those 25 articles. Since the beginning of the pandemic, there has been an explosion of research around racism not because more research is being done, but because more journals are allowing us to finally publish on the impacts of racism and to honor the work that folks have done on this for centuries.

So once we name racism, we then have to identify how it works. Again turning to the work of Rachel Hardeman and Chandra Ford, we see that we have to interpret the findings of our studies begin with the public health critical race praxis that names the primacy of racialization. Racialization acknowledges that the impacts that we see, the disparate impacts that you see for certain racial groups isn't because of their race.

It's because they have been racialized, which means they have been placed within a racial hierarchy in society, that racism then uses to disadvantage folks. And so by naming racialization instead of naming race, we are able to escape the kind of tacit assumption that the implications that we find when we see inequities come from innate differences or biological differences in racial groups.

We know that's not true. Instead it comes from the fact that we racialize people and then subject them to racism. And so when we fail to identify those mechanisms by which racism harms health, our research and our clinical practice effectively exacerbates patient blame. Right. If we don't say this is how racism works, we leave it to people's assumption that it's your fault that you are sicker.

One common and accepted manifestation of patient blame is the undue focus on patient mistrust as a potential driver of racial health inequities. And this is what my colleagues and I were exactly talking about in our Health Affairs piece. So I'm just going to quote that piece because as we are talking about things like the COVID vaccine rollout and trust of the healthcare system, I think it's critical that we acknowledge this during our conversation today.

While patient trust certainly shapes healthcare use behaviors and is an important part of the patient‑physician relationship and I put this in red and bold, "Incessant racial health inequities across nearly every major health index is telling us less about what patients aren't doing and more about what we aren't doing as systems to care for them. To be clear, patient trust will never solve racial health inequities."

I am going to say that again. Patient trust will never solve racial health inequities or narrow gaps in outcome. Eliminating racism does that. And eliminating racism, surprise, garners trust from our patients.

And so to effective eliminate racism, we have to start contending with abolition, with what it means to completely eradicate racism within our field. When we talk about abolishing racism, it's important to contextualize that conversation within the actual material resources populations have at their disposal to protect their health. I think this is a common frame folks use to describe the different allocations of material resources. Right.

If we try to equally distribute resources, it doesn't allow everyone equal access to, in this example, a baseball game. If you try to equitably distribute resources based on need, it could allow everyone equal access to view the baseball game, but not actually to participate. And so what abolition would look closer to is actual liberation, is getting rid of the fence itself.

And as I have been proposing this year, I would also love us to think about how we orient ourselves to the communities we serve, not just as the ways that we distribute resources to them, but the ways that we actually care for them and love them, which is what colleagues and I put forth in our New England Journal piece earlier this year.

We will end here. So this is a paper from one of my colleagues, N. Barcelo, that just came out in Academic Psychiatry. And what it shows is that what the baseball metaphor is missing is first the perspective of those who are impacted. So with the other frame, all of us could see the baseball game. But if we actually center our analysis within the experience of those who are behind that fence, you can't see anything over that fence and you don't know what's there. And if you actually then think about the fact that it's not that people are innately shorter, it's not biological differences that have created these material disadvantages in people's lives, it's forms of racism that include as this example well iterates the effects of mass incarceration and policing on the lives of folks of color, but also the hole, the wealth gap, the education gap, the access to resource gap that impoverishes communities more than others.

And so today when we talk about how we are actually going to address racism in our clinical practice and in our research, we have to begin that conversation from the vantage point of those who are most affected and acknowledge that actually inequality is not innate. It's completely constructed and perpetuated. And then we have to own the ways that our own practice constructs and perpetuates it. So now I will pass it to my colleague Dr. Steiner to continue.

>> Robert Steiner: Thank you so much, Rhea. I should say at the outset it was really Rhea's article in Health Affairs that spurred us to action at the Journal of Genetics and Medicine to try to address some of these issues of racism in publication and how we can prevent perpetuating this. Next slide, please.

So I have some disclosures. I don't think any of them are relevant to today's topic. Next slide. And I should add that the views expressed here are my own. They don't represent ACMG, the journal, its editors, editorial staff or publisher. Next slide.

So launching in, how do we denounce the concept of biological race? I think we all know on this call that race is really a social construct deeply rooted in a system of slavery and oppression. We have propagated long‑refuted and disproven theories about biological race, and yet we still see it in medical publishing. We've taught that genetic differences among the races had an effect on health. Again, that's a problem. Recent studies, however, have found that there's actually very little genetic variation among races. There's more differences among people within each race.

And finally, clinicians and researchers are starting to embrace the fact that race is not an intrinsic biological difference. NHGRI says that race is a fluid concept used to group people according to various factors including ancestral background and social identity. We are also used to grouping people who share visible characteristics like skin color or facial features.

And although these traits are somewhat influenced by genes, it's important to remember that the vast majority of genetic variation exists within racial groups and not between them. Next slide.

We've obfuscated the role of racism in determining health and healthcare. And so why do we need to transform academic publication? In this talk I'm going to focus on genetics and genomics publication because that's what we do at our journal. So the academic publication process through our authors, reviewers, editors, really everyone involved in the journal has unfortunately legitimized scholarship that obfuscates the role of racism in determining health and healthcare. You heard some of this in Rhea's introduction. This renders racism less visible and thus less accessible as a preventable cause of inequity. Publication of research that incorrectly asserts a genetic and/or biological etiology for differing health outcomes in different racial groups is problematic.

And from its earliest days, the field of human genetics and genomics has had a complex and at times really troubling connection with racist ideologies. We need to continue to work to change that and transform publication. Next slide.

So Rhea and others and we are putting out a call for rigorous standards for publishing on racial health inequities. I have five bullet points here. We should define race during the experimental design of a research study and specify the reason for its use in the study. We must name racism explicitly to avoid incorrectly assigning race as a risk factor when it's really racism that's the risk factor for disparate outcomes.

We should never offer genetic interpretations of race. These suppositions are not grounded in science. If race and genetics are discussed together in an article, we should painstakingly delineate the intended implication. We should also make sure to solicit stakeholder input in the research design, review, and implementation.

And we should make significant use of community review boards or patient and patient advocacy group panels to ensure that our research reflects the priorities of populations studied. Our institutional review boards that review and approve research really need to include stakeholders of similar backgrounds as the groups being studied.

And finally we need to appropriately cite the experts, particularly scholars of color who's work forms the basis of the field's knowledge on racism and its effects. Geneticists of color have and will continue to make important contributions in the field and should be recognized and their work published accordingly. Next slide.

Now I am going to give you some examples of the good and the bad that we published in Genetics in Medicine, our journal of the American College of Medical Genetics and Genomics. These are articles that have addressed race and/or racism. And by that, I don't mean that the articles or the science is necessarily bad. I don't want to be overly critical. But I think we could have done a better job. The authors, reviewers, editors, we all could have done a better job of realizing that we were propagating some concepts of racism.

So first of all, some examples where I think we've handled these concepts well. So in the first example, the study was about whether race is a useful variable in understanding genetic variation. This was a qualitative study that explored Black and white general internists' attitudes about the relevance of race in clinical care and the views of the relationships among race, genetics, and disease and looked at the intersection of race and genetics in clinical decision‑making.

These internists, Black and white, concluded that race of the patient is medically relevant, but they did not agree upon why it's important in clinical decisions. And those surveyed were reticent to make connections among race, genetics and disease and asserted that genetics has a limited role in explaining racial differences in health. I told you that they concluded that the race of the patient is medically relevant, but then no consensus emerged regarding why race might be useful in the clinical context. I think that's an important clue here that something's wrong. So race in the clinical setting is a confusing and poorly defined construct. That was borne out of this article. And in the future race may affect decisions based primarily on biochemical or physiologic features. Next slide.

Example 2. This was a scoping review conducted to evaluate the use of residual newborn dried screening blood spots used in research. So every day every baby burn in the U.S. undergoes newborn screening. Blood is collected on dried filter paper. These can be stored for long periods of time and are in many cases are accessible to research. Twenty publications were found that had the potential to address health disparities in their analysis of these dried blood spots.

Sadly, only six stated a specific aim to address a health disparity, and of those, only a single article addressed a chronic condition, heart candidate, where researchers looked at the prevalence of amyloidogenic transthyretin variant among African‑Americans which is associated with heart disease and several other health outcomes. And the conclusion was this resource could be used to gain further knowledge about health disparities but is currently significantly underutilized. Next slide.

Example 3. This was a report describing the return of DNA sequencing results to low‑income Latinx participants recruited through a federally qualified health center. It describes the challenges in returning research results secondary to social determinants of health and presents lessons learned to guide future genomic medicine implementation studies in low‑resource settings.

There were many challenges in return of the results noted including the time lag between enrollment and returning of results. Look at this time. 582 days. There was also difficulty reaching participants, missed appointments, low health literacy, lack of health insurance, reconciling results with limited information on family history, deferral due to acute emotional distress secondary to recent trauma life events. Next.

A fourth example. This study was about an attempt to quantitatively assess the efficacy and equity with which ethnicity‑based carrier screening captures genetics risk. So we do carrier screening in this country. And in the past we based our carrier screening on ethnicity because certain genetic diseases are thought to be more common in people of certain ethnic backgrounds. In this study nine percent of individuals had more than 50 percent ancestry from a lineage that was inconsistent with what they reported as their ethnicity; real disconnect here.

So the conclusion is that self‑reported ethnicity is a really imperfect indicator of genetic ancestry. Limitations of self‑reported ethnicity more importantly led to missed carriers in at‑risk publications. So for ten conditions, patients who did not self‑report the associated ethnicity, they had significantly elevated carrier risk. And for seven of 16 conditions included in curtain screening guidelines, most carriers that were found actually were not even from the population the guideline aimed to serve.

So the conclusion was that there was a substantial disproportionate risk for recessive disease that's not detected when carrier screening is ethnicity‑based. Next slide.

Now some articles where I think we could have done better. So this example, this article suggests that observer‑reported race can be used as a proxy for genetic ancestry, even though they acknowledge that the method can't estimate or account for the genetic admixture of Blacks in the U.S. And this I really take exception to, using automated methods, computer searches to extract references to race and ethnicities from clinical notes to help fill the gaps in data. We really shouldn't be doing that. Next slide.

Another study suggested that race is underreported as a demographic variable in genomic sequencing studies. Substantially increased efforts are needed to sequence patient from underrepresented populations to reduce health disparities. Well, certainly we need to do more research on health disparities and racism and whether genetics or genomics plays a role. But this idea that we should be reporting race more often for no good reason I don't think is supportable. Next slide.

This was a study that was actually reporting a technical standard for the laboratory diagnosis of neural tube defects. And they discussed interpretation of maternal serum AFP levels. And the interpretation of the result of the level should consider multiple factors including things you can see here, including maternal race. One interpretation of msAFP levels put the results in the appropriate context of a priori risk as determined by race and gestational age. And in this article race was mentioned 18 times. Next.

And finally our last example where I don't think we got it right. This research sought to determine whether the association between family history and diabetes was modified by diabetes risk factors and if these relationships were constant across different ethnic groups. Among Blacks, a high familial risk conferred a 20‑fold increased odds of diabetes among lean individuals and only a sixfold increased odds among obese individuals.

And the conclusion was that practically speaking, the results of our study suggest that perhaps in nonwhite populations, a high familial risk of diabetes should be given more weight in the absence of obesity. I think you can begin to see a number of issue with both the way the study was done and the results, when really it's really racism that should be explored in this work and not biologic differences on people of different ancestral backgrounds.

I think we are coming to the end here. Next slide. So in reviewing what we've done right and wrong and in looking at Rhea's Health Affairs article, we felt it necessary to publish a comment in Genetics in Medicine to inform new policies. And this is an article that should be published soon on Taking an Antiracist Posture in Scientific Publications in Human Genetics and Genomics. The authors, Brothers, Bennett, and Cho, proposed eight principles that were scientifically grounded and antiracist to serve as a foundation for the development of policies that addressed unique needs of the field of genetics and genomics. But we need to go beyond mere policies. We all at every step of the process need training on these policies and will benefit from resources that are yet to be developed. Next slide.

So just going through the principles quickly. Race may be used in research studies involving healthcare delivery and etiologies of medical conditions and health outcomes, but only as a sociopolitical category. The inclusion of race variables is especially important in contexts where health disparities are observed. Next.

Genetic ancestry should not be used as a surrogate for sociopolitical race and vice versa. Next. Authors should avoid use of terms that obscure the distinction between sociopolitical race and genetic ancestry as well as terms that evoke historical conceptions of racial superiority. Next.

Variables related to race as a sociopolitical category as with all scientific variables should be ascertained and described in a rigorous manner. Self‑reported ethnicity rather than observed‑reported should be used, but we need to acknowledge that that's not often entirely accurate as we saw with one of our examples earlier. Next. Next.

So authors should explicitly name racism when it is an underlying factor leading to health disparities and should further describe this racism in terms of its forms and mechanisms. Next. Authors examining genetic contribution to health disparities should avoid framing health disparities in reductive terms. Next.

Given the underrepresentation of Black, Latinx, and other nonwhite populations in genetics and genomics research, those involved in publication should prioritize manuscripts with strong representation of these groups even when findings replicate earlier findings in white populations.

And the final principle, number 8. Next. Authors should carefully avoid structuring date tables and other representations of data in such a way as to treat white populations or European ancestry groups as the, quote/unquote, normal in group comparisons.

And then next we just go to the references I think that you've already seen. And I wanted to acknowledge in the last slide, one more slide, the authors of the new article that will hopefully be published in Genetics in Medicine soon. And the reviewers of that article made great contributions. And with that I will stop and hand it over to Daphne.

>> Daphne Martschenko: Thank you. Good morning, everyone. Thank you, Rhea and Robert both for your brilliant presentations. I'm very grateful to be here today. My goal for the next seven or so minutes to be sure we can get to our discussion is to offer up perhaps an unconventional way for ELSI and genomics researchers to brainstorm, address, and put into practice efforts to address structural racism. And I look forward to diving into this more during our discussion. Next slide, please.

So this is a snapshot of the field many of us here today are working in. Those in ELSI genetics live and breathe the tensions of the post‑genomic era every day. We witness in our work what the sociologist E. Nelson calls the social life and social power of DNA. Genetics are both feared and embraced, and they are objects of polarization that have captured the popular imagination. And this polarization stems from an ugly history of using genetic ideologies to legitimize and validate racial‑based differences in our society.

When I first began working on the ELSI of social and behavioral genomics, I was struck by an impasse that I felt the academic community had come to. It seemed to me looking at these media articles, looking at what was happening in the research community that when it came to the risks or potential benefits of social and behavioral genomics, researchers were retreating further into their echo chambers. We were shouting past each other in a way that made me wonder whether constructive solutions to bringing justice, equity, and antiracism into genomics were possible.

And so I've since tried to focus on identifying unconventional approaches to bringing those three principles into everyday research and practice. I'm deeply interested in encouraging us as researchers to place greater emphasis on our social responsibilities to those who are outside of the research enterprise. Next slide, please.

So adversarial collaboration. It's a potential avenue for moving dialogue forward in genetics and genomics. It started in behavioral economics as a good faith effort to conduct debates. And my work over the last few years has been to explore and expand the adversarial collaborative framework to genomics. Adversarial collaboration is a joint research partnership between individuals of differing or opposing viewpoints in different disciplines.

And before I go on, I want to acknowledge that oftentimes when folks hear the words adversary or adversarial, it can carry negative connotations. I would like to break that association. Adversarial collaboration seek to build constructive conversations instead of fueling contentious debates. And the overarching aim of adversarial collaboration is to facilitate an inquiry‑based approach to a subject bridging different disciplines and viewpoints in the hopes of surfacing values that may have previously gone unnoticed.

Importantly adversarial collaboration celebrate bring in perspectives outside of academia. Last month Dr. Matthew and Dr. Bonham spoke about the need to make the biomedical workforce more diverse. To do so calls for us to facilitate diversity among researchers, research projects and research funding. And it also means incorporating the perspectives of those who exist outside of academia. Next slide, please.

The reason why an approach like adversarial collaboration is valuable is simple. Genes do not operate in a vacuum and neither should our research. Inviting more voices into dialogue as adversarial collaboration aims to do can shape the questions we ask of science and how we go about trying to answer them including how we think about and address structural racism.

In my experience, adversarial collaborations provide us opportunities to break down silos and to reimagine our current processes for conducting research by encouraging us to consider genomics within our wider social and historical context, one that is saturated with racial injustice. Meaningful change cannot happen if our research does not acknowledge the real and lived experiences and social conditions around us.

By bringing more people to the table, it's my hope that this framework can breathe new life into conversations on combatting structural racism in genomics. And by that I mean more than including those who have yet to have been given a seat at the table, I also mean including those who traditionally have not wanted to be in discussion with one another or who have not yet thought to engage in dialogue.

Next slide, please. So here is an example of what adversarial collaboration can look like in practice. This is a three‑year working group tasked with identifying the risks, potential benefits and ethical responsibilities of social and behavioral genomics. Our group of around 20 individuals includes historians, genomicists, bioethicists, legal scholars, philosophers and sociologists, some of whom are here with us today.

And it will soon include a sounding board that is comprised of members of the public who will help us think through the factors that might make research in this area ethically or socially problematic, and who will work with us to identify and create solutions to the misuses and misinterpretations of the research.

Importantly, the aim of our working group is not to achieve consensus. In fact, we want to understand and air our tensions and areas of disagreement. Embracing disagreement without the pressure to achieve consensus is a central feature of adversarial collaborations. It's what I think sets it apart from other kinds of collaborative endeavors that we as ELSI researchers see often. And I will be happy to expand on this during our discussion.

That said, I do think that I can speak for our group when I say that we have consensus on our desire to make genomics just and equitable and to prevent the field from legitimizing falsehoods about inherent racial inequality.

Next slide, please. Another example of adversarial collaboration is a paper I coauthored with two social genomicists. We sought to temper claims about genomics research as it relates to education and raised key ethical and social considerations as genetics and education re‑intersect. We concluded by providing recommendations for insuring that genetics benefits all and not just some.

Given the different academic communities we were coming from, the work we produced engaged multiple audiences. It's been cited by sociologists, genomicists, researchers in education and biomedicine. And I believe we were able to reach this wider audience because we brought different perspectives and considerations to life in a single work that was written in a manner accessible to diverse to diverse academic audiences.

And working with these coauthors again and Lucas Matthews who is at Columbia Hastings Center, we are now embarking on a project to build a repository that includes frequently asked questions that come alongside many of the genome‑wide association studies in social and behavioral genomics. Next slide, please.

If I may, I want to end on this final point which is that if we don't reflect on and react to the complementary or opposing nodes of genetics, the social sciences, history, bioethics, and today's cultural, political, legal, and economic environments, we cannot hope to dismantle racism in clinical research and practice in genomics and beyond.

ELSI is well positioned to become the nexus for adversarial collaborations. Interdisciplinarity, justice, equity, and social responsibility are at the heart of the work that we do. ELSI is oftentimes positioned as a secondary addition to clinical research and practice. With adversarial collaborations, I believe that this order could flip because our skills and values are central to the success of these kinds of endeavors. Finally, Angela Davis said that you have to act as if it were possible to radically transform the world, and you have to do it all the time.

Last month, Dr. Matthews spoke about how diversity is messy. So is adversarial collaboration. It is not lost upon me that this is not an easy feat. But the problems it's trying to solve for aren't easy either. So if we commit to it, the inquiry can change, the outputs can change, and the science that is produced I hope will be more robust in its ability to speak to, respond to, and anticipate the realities and injustices of our world. And I'm really excited to talk about this more during our discussion. Thank you.

>> Mildred Cho: Thanks, Daphne. And thanks to all the panelists for those amazing presentations. And just a reminder this recording and the associated materials posted in the chat will be available on ELSIhub.org. And we will also have time for informal discussion afterwards in a separate Zoom room that you should have gotten a link to in your invitation e‑mail.

So I'm just going to launch into some of the many questions that people have already asked. And some of these I will start with some questions that are kind of on a particular theme that I think all of the panelists can jump in and try to address. And that is sort of, given that it's about the categories, the racial categories that sort of the system that we operate in in terms of research and clinical practice use.

And that sort of shaped by things like census categories, things like that. And Gale Henderson asks for example how can we combat the use of census categories? There is also a related question about, from Pamela Payne who says if we don't use race as demographic data, are there suggestions, do you have any suggestions such as using socioeconomic data instead? Eliza Gordon asks what might be a good way to ask about self‑reported ancestry? So I would also add is that something that you think of as an alternative to sort of the categories that we use, or do you have any other suggestions about sort of whether, maybe we should just throw all the categories out. So I would just like to throw it open to the three panelists.

>> Rhea Boyd: If I could begin, I will just say this is a common question. And the first question I am going to take on is, is this the categories that's a problem? It's not the categories that's the problem. And when we say it's the categories that's the problem, it begins to proffer this color‑blind ideology that the better way to look at humans is to ignore racial categorizations.

The categories don't create racism. Racism creates the categories. So when we are trying to study the impacts of racism on health and biology, we then have to use those categories as a way to identify populations impacted by racialization. Impacted by the fact that they are placed into racial groups and then placed into a social hierarchy based upon the racial group that they are in.

So it is critical that we have studies that look specifically at the effects of certain disease processes on racial and ethnic groups. That's critical. There are so many studies calling for increase in collecting racial data just during this pandemic.

An excellent paper I will drop the link to in the chat and it's a paper I have by Sandra Ford, public health critical race methodology, praxis for antiracism research. The very first thing, the central tenet of antiracist research practice is the primacy of racialization which is also in my slide. So we have to acknowledge race by tracking health impacts by racial group, and then the ways that you study it have to acknowledge that racism created the impact or the differences you see between groups not something innate to the groups themselves.

>> Robert Steiner: I just want to add real quickly one question we could potentially ask when people are reporting race or ethnicity, where are your ancestors from?

>> Mildred Cho: Okay. So here is another question which I think Daphne probably thought of, but other panelists as well. There's actually two related questions which is this idea that, you know, I think Rhea mentioned earlier which is that focusing on genetic variants and attributing disease to genetic variants diverts attention away from racism and focuses ‑‑ well, so Stephen G. had raised this issue. But Matt L. also sort of points out that genetics and genetic attribution can be used ‑‑ is sometimes used or thought of as a way to deflect blame, this sort of "I can't help it, it's in my genes, it's not my fault." So I see often there's a tension in that. Especially when we are talking about traits such as sexual orientation or that sort of thing where there's this, you know, great stigma attached to the traits involved.

So I just wonder what you think about whether sort of this idea of kind of calling for less focus on the genetics's cause, how that might play out given this tension?

>> Daphne Martschenko: So one concept I have been thinking about recently is what I'm calling genetic imperialism which is this idea that when we think about genetics, regardless of all the social conditions and environmental factors that are around us, we place genetic factors or genetic effects at the top of this totem pole, there is this colonizing effect when it comes to how we think about genetics and how it permeates the ways that we react to the differences that we see in our society today. So the first thing I would say is that I think we have to be aware that we have this imperialist perception of the rule of genetics. At the same time, I think that it's important to recognize and I think Dr. Bonham spoke about this a bit in last month's presentation, which is that there are potential benefits and there is utility to conducting research that takes into account genetic data.

So to summarize what I think brings out those two tensions is it is one thing to talk about the role of genetics. It is another thing to posit genetics as the be‑all/end‑all. And I think that it is very important for us as we think about how to bring justice, equity, and to combat antiracism in the field to consider that not only do we think about genetics in these various essentialist and fatalistic terms, but we do it in a strategic way.

There's the phenotypes we like to think of in relation to genetics more than others are the way that we have structured our society. So when I think about the example of sexual orientation, sexual orientation is a behavior that we've seen more embracing from the LGBTQ+ community. They have been more open to this idea of there being some sort of genetic effect on sexual orientation.

And there is of course a difference between how people understand and interpret that information and how people understand and interpret genetics research that is looking at cognitive ability or educational attainment. So I think we need to recognize that there is an ethical continuum or a social acceptability continuum when it comes to the different topics that genetics research is beginning to study and explore.

And also to recognize that this genetic imperialism that colors how we think about research conducted in genomics should be ‑‑ we should be interrogating that in everything that we do.

>> Rhea Boyd: I will just briefly add, the reason we don't use genetics to explain health inequities or differences between racial groups is because racial groups don't ‑‑ we don't do it because it's not true, not only because it contributes to patient blame. I just want to continue to underscore that.

>> Mildred Cho: Okay, we have a question from Gail which gets to a comment that you made just recently, Bob, which is how do we prevent ancestry from simply replacing race and ethnicity as a category of biological difference that reifies race as biological?

>> Robert Steiner: Yeah. I don't know if Rhea or Daphne have better answers than I do. I don't have the answer to that. I think we just need to be really careful that our research and our publication and our understanding doesn't attribute biologic factors, certainly there are genetic variations between people of different geographic areas and that's important to recognize. The but when we generalize that to suggest that genetic variance have a biologic difference in difference groups, that's what's problematic.

>> Daphne Martschenko: I would also add that I think one area we need to be especially vigilant about is how we use and talk about ancestry and the potential for ancestry categories to simply replace the racial categories that we use today. And as Rhea pointed out, these categories are constructed and it's the same when we think about ancestral categories.

You see that in the fact that we will talk about European ancestry and African ancestry as these distinct self‑contained categories when we know for example that genetic diversity is very rich within the continent of Africa and to say African ancestry is a self‑contained group is an overly reductionistic interpretation. And so I think we also need to be especially mindful of the conflation of race and ancestry and avoiding ancestry becoming the replacement to racial categories.

>> Rhea Boyd: The only other thing I would add is that one of the central tenets of public health critical race praxis is first we talked about the primacy of racialization to name race and then acknowledge that race is then constructed and put people into this hierarchy and then to identify the mechanism by which it works.

When we identify the mechanism in which he racism works, up to talk about the period of time. Imagine the ways we might try to continue to perpetuate this differences a frame of ancestry in the future instead of just racial groups.

I think it's smart to start thinking like that because we have to start naming the ways that racism also adjusts over time. Racism is systemic. It is a permanent factor of our society that we continue to for as long as we have been here try to group people into these groups and allocate resources based on those groupings.

And so if we acknowledge that it shifts over time, I think our approaches to it also have to shift which I think sometimes in these conversations we imagine that you will just learn one tip and you will apply that tip forever and it will be sufficient and it won't.

We will have to continue to learn the ways in which we still try to regress back to these ideas that race is genetic.

>> Mildred Cho: I think another sort of issue that raises is that, you know, I think we've all now sort of become more aware of the ways in which these sort of umbrella categories that are considered race like Asian or even ethnicity, like, Latinx, can obscure health disparities by lumping in disparate groups that really shouldn't be lumped together, whether by ancestry or any other kind of other rationale.

So let me turn to another question which actually I had ‑‑ I don't know who asked this question, but it's a question, it says that some scholars have been making similar points to these for two or 3 decades. And I know that Vence Bonham, our speaker last time, had written a summary of sort of proposals for dealing with race in genetic research in 2018, I believe.

And it was sort of a review of various proposals. So the question is really about what is different about current efforts or do you see that at this current time that there are ‑‑ there's a sort of window of opportunity for policy and behavior change?

>> Daphne Martschenko: I can start. Yes, I do. I think the moment that we are in feels different. I think we need to capitalize on that moment. It can be very easy to have it take us up for a brief period of time and then for things to go back to the status quo. So there's a lot of intentionality that needs to go into bringing about this change.

But your comment, Mildred, reminded me and I can put it in the chat a paper that Vence Bonham wrote in 2016 about whether precision medicine might move us beyond race. And I think that that also speaks to one of the comments in the chat about getting more granular in our data and how that that can support, can provide better support.

When we think about how we structure categories and our desire to try and make things clean and neat and organized, something that is inherently messy and complex we have to ask ourselves who that serves. And so I think that we are in a moment right now where people have greater awareness of the issues of structural racism, and we have this potential for this idea of precision medicine, which will hopefully move us past looking at people as members of a group and looking at people as the individuals that they are.

>> Robert Steiner: I think we risk taking a defeatist attitude in suggesting people have had ideas on how to combat racism and have been talking about it for decades; that's true. But that doesn't mean that we shouldn't make dramatic efforts today. I do think the timing is right to do it now. I think it's very unfortunate that we haven't taken these steps earlier.

But if we don't do it now, when are we going to do it? So I do see this as a fairly unique opportunity and the time to take action.

>> Rhea Boyd: I will only add I think this moment was created by protesters and uprisings in the streets. So I just want to acknowledge that this moment didn't come from anywhere. It came from lay people basically demanding that we consider racism across society. I will also say I don't think there's going to be a moment when we are past race precision medicine or not.

We know people reflected will be ‑‑ I think what we have to continue to fight against is the inequality that we allow racism to create and that we use racism I guess essentially to create in society and keep recreating and recreating and recreating again. Every new initiative we create to get rid of it, people will continue to use racism as the most efficient way to continue to perpetuate inequality especially in our capitalist society.

So I think we have to continue to challenge racism no matter the current frame that we may operate in. And I hope that this is a moment in which we can do that. But the last thing I will say is there is an ongoing ideologic battle between people who still submit publications and still have primary questions in their research that present race as genetic. This is ongoing. It is not something that is, oh, we are all learning and we are all switching.

This is a fight that has been happening for decades at this point if not centuries. And so that fight kind of continues. And although we are in a moment where people are more open to the idea that race is not genetic as it has been disproven for decades at this point, please acknowledge that there are folks who don't feel that way who will continue to present on the other side of that argument.

>> Mildred Cho: Okay, well, on that note, I think I want to thank all the panelists for proposing some really specific things I think we can all think about and applaud you for bringing tools for the ELSI research community as well as to the genome research community and medical genetics, to use in moving forward, and also to use as part of a discussion that Rhea had talked about that we need to keep having.

And so with that, we will stop and I invite you all to join us in the informal discussion room which is a Zoom link that would have been ‑‑ should have been in the invitation e‑mail that you all received for this session. So I will close this session out and please join us in the other room for more informal discussion. Thank you.