



**ELSI Friday Forum: Structural Racism and Genomics in the Time of COVID**  
**Event Transcript, November 13, 2020**

12:00:18 >> DR. SANDRA SOO-JIN LEE: Hello, everyone. We will get started in just a few minutes, thanks.

12:01:56 Good morning, afternoon or evening, depending where are you Zooming in from today. I'm Sandra Lee from the Division of Ethics in the Department of Medical Humanities and Ethics at Columbia University and I would like to welcome you to our first ELSI Friday forum. ELSI Friday Forum is a new monthly series of the Center for ELSI Resources and Analysis, or CERA. CERA is a multi-disciplinary, multi-institutional center that provides resources to support research on the ethical, legal, and social implications of genetics and genomics, otherwise known as ELSI.

12:02:35 CERA aims to connect a community for scientists, scholars, policy makers, journalists, members of the public and others to engage ELSI issues. CERA is funded by the National Human Genome Research Institute at NIH and is managed by teams at Stanford and Columbia Universities, in partnership with The Hastings Center and Harvard University. CERA's online platform, ELSIhub, launched last Friday and I hope you all had the opportunity to access resources there, such as the literature database, the research instrument repository, the scholar directory,

12:03:08 news and events and many other resources. And I encourage you, if you haven't already, to go to the website, and sign up for newsletters and other events like this one at ELSIhub.org. ELSI Friday Forum will be meeting every second Friday of the month for 1 hour starting at 12 noon, eastern time, so please do mark your calendars. All forums including today's will be recorded and the recordings will be made available on ELSIhub shortly after each event.

12:03:40 Now, just a bit more about the housekeeping, if you wish to use closed captioning, please turn on the CC button at the bottom of your screen. We encourage an active exchange of your ideas with our panelists, so please use the

Q&A button which you will find at the bottom of your screen to ask panelists questions; you can register your enthusiasm for a question and elevate it up the list by using the upvote button in the Q&A box.

12:04:11 The chat box is available for further engagement where you can also find links to resources that will be referenced in today's discussion. And if you have any questions, please do e-mail us at [info@ELSIhub.org](mailto:info@ELSIhub.org) at any time.

So let's turn to today's topic: "Structural Racism and Genomics in the Time of COVID." Over 3 decades ago, this country made a major public and private investment

12:05:16 in sequencing the human genome, in what became the Human Genome Project. At the outset of this major investment, Congress approved a set-aside devoted specifically to ELSI research to address public concerns over the history of eugenics and the potential for genetic discrimination and stigmatization. This year marks the 30th anniversary of the start of the Human Genome Project and indeed genetics has developed in significant and palpable ways over the intervening years, Jennifer Doudna, and Emmanuelle Charpentier were awarded the Nobel prize for their landmark work on genome editing, genetic technology now constitutes the leading edge for venture capital, and increasingly genetic testing has been normalized in and out of the healthcare area. Yet against this backdrop have been the events of unprecedented international crises. Corona virus now accounts for over 1.2 million deaths worldwide and has ravished communities in the U.S. A recent analysis by the Kaiser Family Foundation reveals that the virus is proportionately killing black and brown Americans at rates 3 to 5 times greater than white Americans. With the explicit goal of mitigating health disparities, how do we

12:05:56 as a society reconcile decades of significant investment in genomics with these gross inequities that result in disproportionate suffering and death in communities of color. Last month, the NHGRI issued its strategic plan, and in it is the statement, (quote) "genomics, like other scientific fields, must reckon with systematic injustices and biases fully mindful of their

12:06:23 importance for health equity" (end quote). What does reckoning mean for ELSI research and how should these inform the questions we ask? More broadly, what should constitute a justice-forward genomics research agenda? To begin what we intend to be an ongoing conversation, we are very fortunate to have two leading scholars who have thought deeply about racism, inequity, and health disparities.

12:06:46 Dean Dayna Bowen Matthew is an expert in health equity and public health policy with a passion for public service, she is the first woman to lead

George Washington University School of Law, having previously served as the University of Virginia Law School's William L. Matheson and Robert M. Morgenthau Distinguished Professor of Law and the F. Palmer Weber Research Professor of Civil Liberties and Human Rights. Dean Matthew has held a number of important positions in the policy world. She served as the Robert Wood Johnson Health Policy Fellow for U.S. Senator Debbie Stabenow and as senior advisor in the Office of Civil Rights at the U.S. Environmental Protection Agency. She also is a non-resident fellow in the Center for Health Policy at the Brookings Institution. A prolific writer, Dean Matthew is the author of the book

12:07:34 "Just Medicine: A Cure for Racial Inequality in American Health Care," and has focused her work on health care reform, public health law, health disparities, patient protection, and antitrust laws and civil rights.

12:08:01 Our second panelist, Vence Bonham, is an associate investigator in the National Human Genome Research Institute (NHGRI) within the Division of Intramural Research Social and Behavioral Research Branch. Mr. Bonham also serves as the senior advisor to the NHGRI Director on Genomics and Health Disparities. He leads the Health Disparities Unit, which investigates the equitable integration of new genomic knowledge and precision medicine into clinical settings.

12:08:25 Mr. Bonham and colleagues have developed the first scale to assess health professionals' use of race and genetics in clinical practice, called the Race Attributes in Clinical Evaluation (RACE) scale. Additionally, he created an index designed to measure health professionals' knowledge of human genetic variation and their beliefs and attitudes about its relationship to race.

12:08:55 These are just a couple of examples of how the Bonham group brings empirical evidence to questions regarding the role of genomics in reducing or exacerbating health disparities. So we are looking forward to a great discussion, we will first hear from Vence, then Dayna; their presentations will be followed by a moderated and audience discussion. I want to encourage you to write your questions in the Q&A box and I promise to get to as many of those

12:09:00 as we can for our discussion. And now I will hand it off to Vence.

12:09:28 >> DR. VENCE L. BONHAM, JR.: Thank you, Sandra and thank you for inviting me to be a part of the first ELSI Friday Forum, I'm looking forward to participating in this as this goes forward. I want to start my comments today (just go back to the disclaimer, yes, stay there for a second. I wanted to make a comment) that I just want to make clear to all of the viewers today

12:09:54 that my statements and my comments today are not representative of the National Human Genome Research Institute, or NIH, or the Department of

Health and Human Services, and these are my views as a scholar and researcher studying issues with regards to race. I also want to state that my views are not outlining the NHGRI funding priorities or representing the ELSI program.

12:10:26 Next slide. So, my work, as Sandra stated, over the last 15 years has really been exploring the questions around race and genetics. Our understanding of how race is used currently within the field of genetics and genomics and particularly I've been focused and interested in what happens within the clinical encounter and how race is used by healthcare providers in thinking about genetic variation and difference. Next slide.

12:11:03 So, I wanted really to identify 3 milestones with regards to the field of genomics that has happened over the last 30 years, but I want to start with this: in 2000 at the time of the completion of the draft sequence of the Human Genome Project with the regards to the sequencing of the human genome, the statement made by Dr. Francis Collins at the Rose Garden with President Clinton and Craig Venter. And Dr. Collins stated "I'm

12:11:22 happy that today the only race we are talking about is the human race." This statement by Dr. Collins had two different frames to it, one was the completion of this race between the private sector and the government with regards to sequencing the human genome, but also this question about race, and how race is used, and understanding of difference. That we are one human race and understanding that. So, this was 2000, just at the sequencing of the initial sequence as part of the Human Genome Project but over the last 20 years, there clearly have been some significant changes. Next slide.

12:12:10 So my work, as I stated, has really focused in on physicians and other health professionals and how they think about and use race and understand and interpret race. And so, I conducted a study of general internists as a national study of general internists where we asked them a number of questions about their use of race in their clinical practice and we asked this statement:

12:12:45 "biological differences between racial groups affect health outcome differences." You see here with this data the vast majority of all the physicians - this was a study of about 780 general internists across the United States - stated that they agreed with this statement that race was a biological difference with regards to health outcomes. This issue is of an interpretation and use of race in clinical care and in clinical decision making.

12:13:22 I have continued to explore this issue with regards to how healthcare providers and physicians, nurses, nurse practitioners use race, to recognize that this is an important area for study for ELSI scholars and for the field of genomics and I argue that we have a responsibility to study the use of race and to interpret

and understand the use of race and racism. Next slide. So here, 2018, two articles from 2018 in the conversation in the public

12:13:59 domain and this question about social identity and genomics, how do we think about individual social identity and how do we relate that to interpretation of scientific findings and interpretation of studies – or misinterpretation of studies. These two articles, one connecting with an article that was an opinion piece in New York Times and the other story about white supremacists and their views about genetic difference and how they have used genetic

12:14:43 findings and genetic studies to support their positions. Next slide. But the conversation that we're having today is in the middle of the COVID-19 pandemic that is getting worse by the day. Where it clearly has identified the significant disparities that we have in this country, and globally, with regards to the morbidity and mortality related to this pandemic, and my question to you and my question hopefully we can have in this conversation, is: what

12:15:13 if we didn't have race and ethnicity data on the COVID-19 pandemic? I argue we must have that data to study racism, to study structural racism and its impact with regard to the disparities that we see. We don't need that data to understand genetic variation, but we do need that data to understand how people are treated differently or because of their social setting, they are at higher risk of the virus, or when they get the virus, the potential

12:15:53 for mortality is higher. Next slide. So, as Sandra stated, the National Human Genome Research Institute a couple of weeks ago published a vision for the human genomics field with regards to the forefront of what is needed to improve health. Included within that vision statement was a set of 10 bold predictions and I think it's our responsibility as ELSI scholars to think about those bold predictions and particularly one I want to highlight for our

12:16:20 conversation about race today. One of the bold predictions stated “research in human genomics will have moved beyond population descriptors based on historic social constructs such as race in 10 years.” I think this is an important statement to think about: what does that mean and what are we talking about? The issue of thinking about how do we design studies in a way when we talk about

12:16:53 and explore human genetic variation that we are not using social descriptors to talk about populations and use group and reify race as a biological construct. I think that is important as we move forward within the field of genomics and I argue that this is an important area for study across the field of

genomics but particularly for ELSI researchers, I would like to argue that ELSI researchers must study the history

12:17:22 of race and ethnicity and genetics and why, when we look at race, and use race, that it is important to understand and study these differences. So, the study of the history of race and ethnicity in genetics and how, why, and when race and ethnicity is used in genetics and genomics today, I argue, is an important area of scholarship for ELSI researchers.

12:17:54 I also argue that it's important for ELSI researchers to explore the ethical, legal, and social issues of genomics and structural racism in research, in clinical settings, and in nonmedical settings. Next slide. I want to close my comments, we were asked to give some comments that were related to 3 questions that framed this session today.

12:18:32 And one of the questions was with regards to what does justice-forward research look like in genomics? And I want to revise the question slightly to say 'what does justice-forward research look like in ELSI scholarship and ELSI research?', and identify 5 areas that I think are important, and then a charge and a challenge to the ELSI community. So, first, I believe ELSI scholars need to study the inequities in genetic services and genomic medicine.

12:19:10 I think ELSI scholars need to study the social identity and its role in genomics, how does social identity connect with race and ethnicity, how is it used in the field of genomics? I believe that ELSI scholars need to study the history of genetics and genomics research and its reckoning with race science in the 21st century. The field of genetics and genomics has such a long history that is connected with systemic racism that must be explored, and I think ELSI scholars are in the position to do that work.

12:19:43 I believe that ELSI scholars need to study the use of race in genetics and genomics; that is the area of work that I do, of studying what happens, how is race used? I believe we need to do more of this work, both in the area of research but also in the clinical setting, to explore the use of race and understand that from the framing of an ELSI scholar. But I think it's extremely important that ELSI scholars study

12:20:14 racism in genomics and in ELSI research, the ability to study racism, to interpret it, and to help to move forward the work within the field of genomics. And I finally wanted to make a charge to the community that I think it's important in our ability to move forward in a justice framework, and that is to establish an agenda to increase the diversity of the ethical, legal, and social implications researchers and scholars.

12:20:45 We need to do better as a community of scholars to make it much more representative of our country, to bring different perspectives and different views to the conversation and this includes around race, science, around racism, and the broad areas of research that ELSI is involved in. And so, I charge for all of us to think about how are we helping to create a more diverse ELSI research workforce? Thank you, Sandra.

12:20:54 And so at this time, I give it over to Dayna for her comments.

12:21:25 >> DR. DAYNA BOWEN MATTHEW: I thank you so much, Vence, I feel very honored to be on this program with you. Vence, I have fan-girled you for quite a long time and love your work. Thank you to Sandra Lee and to all of the creators of this important series, I thank you for the opportunity to bring my perspective. Next slide. I have no conflicts to reveal or disclose. Next slide.

12:21:57 But I do have goals that pick up exactly from where my colleague Dr. Bonham just left off. His call that the genomics community and the ELSI scholars in particular study racism, I consider my call in that I will have the opportunity in the next 5 minutes to help you define racism and particularly structural racism, my emphasis will not be only on the role that law plays but I would like to ask the audience

12:22:30 with me, as I speak, to interrogate the role that science, medicine, and public health played in creating the structures of racism that I wish to discuss. I'll do that by identifying the connection to health and then suggest my lessons in the form of 3 cautionary tales. Next slide. So, what is racism? I'll start by leaning heavily on the work of Dr. Camara Jones who did a magnificent job of explaining these things about racism.

12:23:08 One: it's a system. We're not talking simply about attitudes or prejudices that affect individuals but a system of structuring opportunity and value. So, racism does two things at least according to Dr. Jones' very apt description and definition. One, it hierarchically arranges people as to their relative worth and value in a population relative to one another. So, there are more valuable or supreme races and less valuable or inferior races.

12:23:39 Of course this thing called race which she has in quotes reflects the fact that she and I reject the biologization of race as a social construct. Secondly, what does racism do? It unfairly distributes all of the resources and all of the opportunity and all of the power that a society has to share. So. these two things are made structural (next slide)

12:24:15 when we see that racism becomes a solid, replicated, institutionalized form of organizing society and its resources. So, this is a diagram that sets out my conceptual framework for a book that I'm working on now. To distinguish at the

top of the diagram from interpersonal prejudice, like I said earlier about individual attitudes or individual feelings of bigotry, to the bottom of this pyramid. I had in mind when I created this,

12:24:45 if you remember Tom Frieden's impact pyramid where the bottom is where the action is, if you will, it's where the real solid change in influence is lodged. So, at the bottom, structural racism, how does it become structural? My argument is that it does so by law and then the cooperation and organization of all other institutions including research, medicine, clinical science, science, all of those institutions then, are influenced by

12:25:22 the structures that law creates. In the middle of this diagram, you see that these structures will influence all of the social determinants of health, that is the social context in which we live, work, and play. So that racism becomes medical truth or becomes health outcomes because of the social impacts that the structural racism has. So, that is my theoretical construct for what is structural racism. Next slide. So, the definition then is that we have a system of hierarchical preference,

12:25:52 it's institutionalized by the power of history and law, it assigns status, it accords that status to a social construct, and allocates resources; that is how I define structural racism. Next slide. How is it operationalized? Well, I said through history, through the injustices, and where do we see this? I will now turn to the exact same example that you used, Venice, where do we see this history manifest in COVID-19?

12:26:28 But make no mistake that the resources that structural racism allocates include clean air and clean water. Inferior populations don't get it, superior populations do get it. Access to healthcare, healthy food, jobs that allow one to stay healthy, and so on and so forth, these resources are allocated along a strata that include or reflect the structural allocation of worth, superiority and inferiority along a continuum. Next slide.

12:26:55 So now let's see how it's revealed in the pandemic, next slide. These two I'll go through quickly, this is knowledge we know as we are approaching November 9<sup>th</sup>: 10 million cases, 237 thousand deaths. I feel the need to say that so that we remain mindful of the adverse and serious impact that this terrible pandemic is having. Next slide. This slide is almost identical, comes from the same source, to

12:27:16 show the disparity of the morbidity and mortality, if you are African American, you are 2 times more likely to die from COVID, if you are Native American, you will be hospitalized more than 5 times more likely than your white counterparts. Okay, so we see the inequality. Next slide.



12:27:49 Now, let's look at why we have those inequitable outcomes. Well, many people are talking about underlying co-morbidities, on the left, yes, those underlying co-morbidities certainly are connected to, predispose the populations that are disproportionally impacted by COVID, cancer, COPD, diabetes and so forth. But let me quickly call your attention to the underlying social co-morbidities, the risk factors of not only of race and ethnicity,

12:28:19 but how race and ethnicity is expressed in social status, where you live, how you work, what your neighborhood conditions are. Let's see how those risk factors, those social co-morbidities map onto the medical conditions that are underlying and therefore make some populations more vulnerable than others to hospitalization, death, and poor outcomes in a pandemic such as the COVID-19 pandemic we're experiencing. Next slide, please.

12:28:50 So COVID-19 only reveals structural racism, it did not create it, it did not introduce it. Instead, COVID-19 is a reminder, if you will, an illustration of inequality that already existed. So these data on the next 3 slides are from New York. (Please go back one slide. Back and back and again. These data are from New York.)

12:29:20 The residential inequality that required people who were in cities that packed housing like this so you have to ride an elevator, that your common spaces are unavoidable, that these housing options are located in neighborhoods with few healthy food options, few green spaces, likely less clean air to breathe because of proximity to pollution sources, and so on.

12:30:02 These are the kinds of housing realities that are mapped onto populations by race because of systematic and structural racism and therefore, create the health outcomes that are underlying co-morbidities for a predisposition to adverse outcomes to COVID-19. Next slide. This is also true with respect to employment inequality and again COVID-19 is merely placing a mirror to reflect what has been true far before this pandemic and has been true for historic reasons, as I will show later.

12:30:33 But 30 percent of all bus drivers in New York are black or brown, 20 percent of all food servers are black or brown. All the people who ride public transportation where you are exposed, as this picture suggests, to the transmission of COVID or have an increased exposure to the transmission of this airborne infection, were black and brown, and the fact is that I, and you, and most people on this call, do not have to ride public transportation in order to arrive at our essential worker jobs.

12:31:07 I'm sorry to pause at one example that is not on my script but it's poignant and I have to say it. I think about agriculture workers who are in

California who were, before the pandemic in March, undocumented and worked as guest workers (or less, in terms of status) in fear of their safety and in fear of deportation. When, however, the pandemic hit, letters literally went out to this population of Latinx workers to tell them

12:31:41 they were now essential and had to show up to work during the pandemic. What a difference a day makes! What we call essential has made structurally racist decisions about exposure to this disease and other disease modalities. Next slide. This is also true for education. I'd need to linger here for longer to make the connection, but I'm going to surmise that this audience knows the connection between education, opportunity, and disease and poor health outcomes, that they predispose all of the other social

12:32:12 determinants of health that had the effect of exposing people to COVID-19 disproportionately, but I include this for your reference in case you aren't aware of that difference. Black and brown people are more likely to be represented in inferior schools, that give them access to inferior jobs, that give them access to inferior income, and therefore inferior housing, creating a structure of racism that has predisposed them to the co-morbidities and to this disease and others.

12:32:48 Next slide, please. So then, what we are looking at is a system that has bubbled up from the bottom of this diagram and impacted the social determinants of health and all the health outcomes because of structural racism. Next slide. So now you see how structural racism is operationalized, let's talk about the relationship between structural racism and history as it pertains to clinical science, research scientists, and public health experts. Please, next slide.

12:33:26 So I'm going to (next slide), I'm going to fly through some of these, you remember that the 3 elements of structural racism included legalized dehumanization, this is the place I want to focus your attention on for your inquiry, your self-interrogation, if you will, of the ELSI scholar's role in implementing a justice-forward, a justice frame, of how genomics research should proceed. I intend by this slide to show that it is a very short distance

12:33:55 to travel, from the dehumanization that on the left is depicted by weighing a woman in order to determine her worth for sale and the current regime of denying water to women and men because of their worth based on race, ethnicity, and socioeconomic status. My suggestion to you that the legalized dehumanization is not only history, but the past is not past. It is present.

12:34:28 And that is why structural racism continues to operate today. Next slide. The second component is legalized inequality. You see on the left all of the segregation laws that are familiar to you from the Jim Crow era and on the far

right you see that red-lining, which I'm sure is familiar to many people, creates a location for these residential segregation laws to have effect on where people live and the access to power, resources, and opportunity that they have.

12:35:07 Next slide. Lastly the third component is unequal protection of the law. It is against the law to discriminate, but we know from Flint and hundreds of other examples contemporary to 2020 that discrimination or disproportionality does occur today. So those are the 3 elements (next slide) of structural racism. Let's see how it operates. I'm going to use as my example, Charlottesville, Virginia, you remember it because of the tiki torches and the marching of the Unite the Right rally. I want to introduce this legal statute from 1912 that created segregation, you don't have to read all of it to

12:35:38 understand that before this statute people lived where they wanted, and by law after this statute, they were required to separate by race. So here's the law in 1912. How does it work? Next slide. In 1912 (this is a 1907 photograph) in 1912 that law imposed segregation on this map of Charlottesville, Virginia. This is a Sandborn Fire Insurance Map of Charlottesville Virginia; this series of maps will show you what the impact

12:36:15 of this 1912 law was on the lived experiences and the access to healthy living that various populations in Charlottesville had. So to orient you, Union Station is in the center in red and the colors you should see here are pink and yellow, pink are industrial buildings, yellow, largely residential buildings, so you now you see in 1907, most industry is to the right or east, most residential population are to the left or west and, by oral history, mixed race.

12:36:54 Next slide. Fast forward to 1920 and you have here pictures that are enlarged of separate sections of Charlottesville, Virginia. On the left, Woolen Mills, because by 1920, the segregation ordinance had worked its magic and Woolen Mills was an all-white, industrial, blue-collar worker neighborhood, and on the right, Starr Hill was all-black, also upper-to-middle class neighborhood. Look at a few differences; one, look at the density of population in 1920.

12:37:22 On the right for the black neighborhood, on the left for the white neighborhood, number two, look at the water that provides recreational spaces, open space, green space for the mental health of the white population on the left and that is absent for the black population on the right. But here is the third observation and where I would like you to consider the role of scientists, of public health specialists, of medical professionals.

12:37:52 Understand that the board of health in Charlottesville, Virginia, like in many cities of this time, were populated by those from the local university medical schools, so it was doctors, deans, clinicians who made the decision that,

if you looked closely, the water mains that are servicing the residential homes in the white working-class neighborhood traversed in and out of each home

12:38:25 and home block to bring water, sanitation, and sewage to each individual home. Remember the Sandborn Fire Insurance maps were a picture of the physical space that a fire insurance company would be concerned with and so it is useful to us to rely upon those water main pictures on the right-hand side of the black neighborhood and see that water mains, sewage and plumbing only went up to the pink

12:39:02 commercial buildings but not into the residential neighborhoods. These were public health decisions, these were legalized dehumanization decisions. And these decisions are what I mean when I say the past is not past, it's not even dead. Next slide, please. If you look at the left hand 1920 map and the right hand 2018 map, you see Union Station is now the center of not only commercial activity

12:39:33 but it is also the center, still today, of the black and brown neighborhoods in Charlottesville, Virginia, the darkest concentration or the concentration of poor and blacks and Latinx populations in Charlottesville. I want to empathize that this is just one example, any city I speak in I can do this exact same progression, this is not a story about Charlottesville, this is a story about America. Next slide.

12:40:05 I will go through these quickly, these differences are manifest in graduation rate disparities, next slide, they are manifest in income disparities and manifest in health disparities. When you look at these carefully, the data are not available from 1950 to 1990 but the difference in black/white infant mortality, even though the absolute rates are vastly different, infant mortality rates have gone down from 1930 to 2015 when these data end, the difference, however, the gap

12:40:35 between black and white infant mortality has not changed since 1930. Next slide. So what does this mean for us? Here are my 3 cautionary tales, I will do them quickly. Number one, (next slide) I want to reiterate every single one of the recommendations that Dr. Bonham gave but let me say that the first cautionary tale is to make the mistake of thinking that the inquiry that you are engaged in, scientific inquiry,

12:41:04 is complete if you do not consider the effect of race and ethnicity in the context of social risk factors. Here I will say it is important to note that you are not simply looking at the correlation between race and genetic outcomes, you are looking at the correlation between racism, particularly structural racism and health outcomes. Next slide.

12:41:42 The second, is not to be fooled by this notion of color blindness. Next slide - I mean the next picture of this slide, please. We can - because of the climate that we live in, the danger of the conversation being difficult and misunderstood - we can make the mistake of forgetting that there are scientific and genetic differences, that there are biological differences that can be traced, even though race itself is not a biological construct

12:42:14 and I put these two pictures in juxtaposition or collection of pictures in juxtaposition to remind you that you are not conducting scientific research in a bubble, that you are conducting it in an environment that makes us all concerned about race and ethnicity and the misuse thereof for very good reason. So the third cautionary tale (next slide) is that you as scientists are not immune from this terrible discourse

12:42:38 and this terrible divide that we are all subject to on race and racism. Eugenics is not a thing of the past, it is a thing that we must be vigilant and aware of and cautious against even today. So, I'll conclude there. And look forward to the questions that have been raised by my comments.

12:42:56 >> DR. SANDRA SOO-JIN LEE: Thank you so much for those tremendous remarks both from Dayna and Vence and we do have some questions, we had over 650 folks registered for this event so I know there are many of you who probably have more questions so I encourage you to submit those in the Q&A box.

12:43:19 But let's start with this first question and it's a comment and a question from Elysia Davis and the question is "How can we challenge our health care colleagues who staunchly believe that differences and outcomes are due to biological differences rather than social disparities?"

12:43:50 >> DR. VENCE L. BONHAM, JR.: I'll start. I think we are at a very really important tipping point with regards to medical education and training and thinking about the role of race and differences in clinical care and I actually think that students, medical students are helping to push this agenda that some of the things that we do, some of the clinical guidelines and some of the algorithms that we use are clearly showing that they are racist.

12:44:17 So, thinking about how can medicine can become antiracist is to really explore these questions, I think education, I think opportunities to engage in conversations, difficult conferences for many people, about these issues about why do we see these differences? what are these differences? Is it race? or is it an understanding of maybe genetic race and genetic differences or environment and how we explore those issues?

12:44:33 So, I think education is a major part of it and I also think it's an antiracist agenda for medicine and I see that happening today in many places across our country.

12:45:04 >> DR. DAYNA BOWEN MATTHEW: I'll piggy-back on that to say my answer is one word and it's "relentlessly." How to challenge that? You have to challenge it relentlessly and this reminds me of the up-coming Thanksgiving dinner: so many students have asked during this time of presidential election debates and so forth, what do I do with uncle so-and-so? You challenge them. What do I do with the teacher that makes the racism comment in class? You challenge them.

12:45:19 We won't change this unless each of us take the responsibility for changing the conversation and elevating truth and elevating science that is responsible and antiracist.

12:45:47 >> DR. SANDRA SOO-JIN LEE: Great, thank you. We do have another question, this comes from Dave Kaufman, "Yesterday we saw a publication in *Nature* correlating genes purportedly associated with educational attainment, to another trait, voting behavior. Do either of you care to comment on genetic studies of behaviors that we know are related to social inequities?

12:45:49 >> DR. VENCE L. BONHAM, JR.: Dayna?

12:46:16 >> DR. DAYNA BOWEN MATTHEW: So, in my PhD training, correlation is not causation was like drummed into my head over and over again. And one of the things that I have to say must be challenged relentlessly is the kind of publication (I haven't seen this one but I can only imagine, I hope somebody will put it in the chat so I can add it to my list of horrors).

12:47:00 I have very little tolerance for the kind of research that capitalizes on inference and the exclusion of context in order to make a racist point. I'm not saying that is the nature of this study, I haven't read it. But since correlation is not causation, incomplete correlation that suggests causation is even worse. So what I hear in the questioner's summary of this article is that we have looked at a correlation between race, behavior, and voting.

12:47:20 If you treat race as though it is biologically dispositive and significant instead of racism and the racial context that has been afforded people by race then you make an inference of causation that is racist.

12:47:44 >> DR. VENCE L. BONHAM, JR.: I would just add that I think this is an important area for scholarship within the ethical, legal, and social implications area, to really to tackle these issues above the messaging that comes from these various research articles as well as kind of looking at the analysis and

understanding, and pushing what are the questions that are actually being asked by these scientists?

12:48:03 And so I see issues around IQ, educational attainment and a variety of areas that there is a need for more scholarship that is really framing it in understanding of the context of issues of race and racism.

12:48:30 >> DR. SANDRA SOO-JIN LEE: Okay, Vence, we have another question for you. Here, "Great talk," says Stephen Modell. He asked "Do you see aims, ancestry, informative markers, or some other means, social/scientific displacing the use of race in ELSI genomics research 10 years from now," and I think he is referring to one of the bold predictions.

12:48:57 >> DR. VENCE L. BONHAM, JR.: The answer is no. I think in ELSI research that there is a need to study the use of race and the study of race science and to study racism and so that within ELSI research, I see an important future for scholars to explore issues around race and racism. Now, do we need to think about within the field of genomics more broadly of how do we interpret and describe

12:49:19 populations when we are conducting genetic variation studies? I think the answer is yes and I think that we need to be thinking about this and exploring this in a number of different ways but from the perspective of ELSI research and thinking about the use of race and thinking about studying race, I think we have an important future to do that.

12:49:37 >> DR. SANDRA SOO-JIN LEE: Dayna, this question from Jamil Scott, "How do you define, measure, and build consensus around the concept of justice and then make it operational in ways to lead to improved health outcomes for all.

12:49:41 >> DR. DAYNA BOWEN MATTHEW: I got the easy question, I see.

12:49:44 >> DR. SANDRA SOO-JIN LEE: (laughter)

12:50:16 >> DR. DAYNA BOWEN MATTHEW: Let me say that each of us has a different role in defining and operationalizing justice, but I really appreciate the question because it's "what do I do and how do I help?" Let me answer this for ELSI researchers, I too want to quote Francis Collins, he wrote in a 2004 article that a true understanding of disease risk requires a thorough examination of root causes. One of the things I want to emphasize from my presentation is that a root cause of structured racism is the organization of law that was then

12:50:54 operationalized by science, the organization of health access that has been operationalized by clinical medicine. What I think we must do is recognize the ethical responsibility to reverse that injustice in our role of creating it. Right? So that all of us have played a role, all professions, health professions, medical

professions, researchers, have created a role in erecting structural racism and therefore have a responsibility to dismantle it. I think that is the

12:51:37 first shared understanding; justice requires accountability; it requires the reversal of unfairness, and it requires the advance of truth in science and equity for all. That is why the root cause is so important. That is why not relying on what Francis Collins calls these poorly defined terms 'race' and 'ethnicity,' they are flawed surrogates for environmental, for social, for other disease causes. So you must, if you are an ELSI researcher, get to the root cause, stop using race as a poor substitute, or surrogate, for what are social causes.

12:51:48 And third, always view your responsibility as an ethical one to reverse these contextual inequities that have resulted in health disparities.

12:51:51 >> DR. VENCE L. BONHAM, JR.: Here, here!

12:52:15 >> DR. SANDRA SOO-JIN LEE: Jim Tabery asks a question, "genomic medicine, particularly in the form of pharmacogenomics has become more and more aligned with private industry, as examples, bio tech and pharmaceutical companies over the last 25 years, I would be curious to hear from our speakers how that relationship impacts inequalities?"

12:52:38 >> DR. VENCE L. BONHAM, JR.: I'll start. You know, I think that is part of a larger context of our health care system in the United States and inequities that we have in our health care system and access to all types of services, including pharmacogenomics but thinking more broadly and I think we have to grapple with the inequities with regards who has access and who can benefit

12:53:05 from the exciting things that are happening within the field of genomics that can improve health, but challenging us to think about these issues of costs and thinking about are there new frames. I argue that creates a whole area of scholarship for ELSI researchers to push a conversation around this issue of equity and what does equity mean in fairness; how do we use that as we have new technologies

12:53:14 coming to the clinic and the role that it can play in improving health.

12:53:38 >> DR. DAYNA BOWEN MATTHEW: The only thing I want to add is that if we agree - as I would like to encourage you to consider agreeing with me - that racism is a fundamental cause of health disparities. Right? And I'm taking this from Link and Phelan's fundamental cause theory in 2015, they identified racism as a fundamental cause of health disparities.

12:54:13 If we agree that that is the case then pharmacogenetics and all other interventions intended to improve disease outcomes will also replicate or even widen disparities if there is not an intentional focus on antiracism, right? And we



can think of cigarette cessation, smoking cessation as the paradigmatic example. Any solution you insert into a layer on top of a structural racist environment

12:54:23 will simply exacerbate those inequalities unless you intentionally work against them, that's what a fundamental cause is. So, I just want to add those in as well.

12:54:53 >> DR. SANDRA SOO-JIN LEE: I will take one question that has come up in the chat and it's about research findings that suggest that scientists from underrepresented racial and gender groups tend to prioritize different research topics, So this is a question about reflecting back who is actually conducting the science. We know that studies that have shown the diverse team leaders and members produce more novel research that tends

12:55:26 to produce different kinds of questions, and I noticed that Shawneequa Callier in the chat has noted one of the studies of differences in terms of funding by NIH between African American scientists relative to white scientists and I am wondering if you can comment on whether this is a form of structural racism, structural marginalization and what could be done to try to dismantle that?

12:55:55 >> DR. VENCE L. BONHAM, JR.: I'll start and give it over to my dear colleague, I would say yes, it is, and I think that this is an area that NIH has a spotlight on as a problem in addressing this issue and I think that there is a need to much more transparency with regards to data, to understand issues around funding and differences among applicants and individuals who ultimately get grants from NIH and other organizations

12:56:06 and I think this is an issue that we have to think about and grapple with and there is a recognition that that is important to do.

12:56:32 >> DR. DAYNA BOWEN MATTHEW: I have little to add except that grapple is the operative word there. I just wrote to my students yesterday that democracy is messy, diversity is messy. When you are really committed to diversity, equity, and inclusion, it means that the status quo will change. It means that the questions will change. The inquiry will change, the methods will change, why? Because voices.

12:56:47 who were not inquiring and scientists who were not invited before are now present. That is a good thing. But it's a complicated and messy thing; if you are committed, you have to stick it out through the messy parts as well.

12:57:11 >> DR. SANDRA SOO-JIN LEE: We are nearing the end, I will allow you both to just give some final comments and if you could focus on the concept of this justice-forward genomics research agenda, what would you leave us with in terms of steps moving forward?

12:57:40 >> DR. DAYNA BOWEN MATTHEW: I would leave you with one thing that I would implore and I'm borrowing this again from Francis Collins, I guess he is our muse today but research must move beyond weak and imperfect proxy relationships of race-and-this and race-and-that and instead define much more proximate factors that influence health. Those are social, those are environmental, and those are the

12:57:50 proximate factors that you must be focusing on in order to really have a justice-forward research agenda.

12:58:23 >> DR. VENCE L. BONHAM, JR.: So my comment would be this. To really move forward a justice-forward, ELSI research agenda really requires us to look at who are the scholars that are coming behind us. Are we really creating the scholars that are reflective of the diversity of this country? From various ways of thinking about diversity to actually being the next scholars that are asking the questions and interpreting the data.