AUDIO: Recording in progress.

MILDRED CHO: Good morning, afternoon, or evening, or in the case of one of our speakers, the middle of the night? Depending on which part of the world you're Zooming from today. I'm Mildred Cho, and I'm very delighted to host our January ELSI Friday Forum, which is entitled "Ensuring Equitable Use of New Genetic Technologies: Lessons from Eugenics." And I'll just continue on with the introductions as we wait for people to trickle in.

This forum is hosted by the Center for ELSI Resources and Analysis and held on the second Friday of every month for an hour starting at noon Eastern Time in the U.S. We also have a Zoom room reserved for more discussion immediately after the panel for 30 minutes. For those of you who might be new to CERA, we provide resources to support research on the ethical, legal, and social implications of genetics and genomics, and we serve to support scientists, journalists, members of the public, and others. It's funded by the

National Human Genome Research Institute at NIH, and managed at Columbia and Hastings University in partnership. I encourage you to visit the online platform ELSIhub.org for the recording and transcript of this forum and related references. In particular, please use the link in the chat to access our newest ELSIhub Collection, "Social Norms in Selective Reproduction: Implications for the Wide Offer of Genetic Screening Technologies." This essential reading list is curated by Ainsley Newson and considers the social context on individual reproductive choices and explores the arguments for the expansion of reproductive screening technology to whole populations and the ethics of state involvement in genetic screening. Please also go to the website to join the ELSI scholar directory, sign up for newsletters and other events like this one, at ELSIhub.org, and also get daily updates and news on Twitter.

So, just some quick housekeeping. If you wish to use closed captioning, please turn on the CC button at the bottom of your screen.

The panelist presentations will be very brief in order to conserve time for discussion, so please use your Q&A button, which you'll find at the bottom of your screen, to write questions for the panelists at any point during the discussion, and we'll try to get to as many as possible. You can register your enthusiasm for a question and elevate it up the list by using the upvote button in the Q&A box. And the chat box is available for further engagement, but we -- please try to use the Q&A box for questions. And otherwise, if you have other queries, please e-mail info@ELSIhub.org at any time.

So it's my pleasure to introduce our moderator for today, Osagie Obasogie, who is the Haas Sistinguished Chair and Professor of Law at the UC Berkeley School of Law in public health as well. He received his BA from Yale, his JD from Columbia Law School, and also from Berkeley, where he is a fellow with the National Science Foundation. His scholarly interests include bio-ethics, race, and inequality in law and medicine, policing, as

well as reproductive genetics and technologies. So again, it's my pleasure to introduce Osagie. So you can take it away. Thanks.

OSAGIE OBASOGIE: Great. So thank you so much for that introduction, Mildred, and I'm really excited to be here to moderate this important conversation on reproductive and genetic technologies and placing some of the ethical and regulatory conversations that we're having about them in a deeper historical context.

So it's my pleasure to introduce -- (clears throat) Our two panelists for today. Our first panelist is Dr. Emily Klancher Merchant, who is an assistant professor of Science and Technology Studies at UC Davis. She teaches courses on gender and science, health and medical technologies, and data science and visualization. Her first book is titled Building the Population Bomb, published through Oxford University Press, and it examines how human population growth became an

object of scientific expertise and government and philanthropic intervention in the 20th century. She's also a member of the School of Social Science at the Institute for Advanced Study where she's researching the history of genomic data in the social sciences over the past 100 years.

Our second panelist will be Dr. Lisa Dive, who is a research fellow at Sydney Health Ethics within the University of Sydney. She's joining us at 4:00 a.m. her time, so we really appreciate her efforts. She has a background in analytic philosophy and health policy, as well as a postgraduate degree in bio-ethics. Her research explores how analysis of fundamental concepts can help in responding to many of the ethical challenges that arise in medicine and health care systems. And she has a critical interest in genetics and genomics.

So Emily will first present for about eight to ten minutes, and Lisa will follow, and then we will have a group conversation with the audience. So, Emily.

EMILY KLANCHER MERCHANT: Thanks, Osagie. And thank you, Mildred, for organizing this and inviting me.

So, why the history of eugenics still matters. Next slide, please.

People who underwent IVF in 2019 or 2020 had a unique opportunity available to them. In addition to screening embryos for aneuploidy and a variety of single-gene disorders, the new start-up Genomic Prediction also offered to screen for lifetime risk of a variety of diseases, including what the company termed intellectual disability. Next slide.

This particular screening was quietly dropped from the company's menu of services at the end of 2020 due to public disapproval. It clearly smacked of eugenics. But even those who advocate for embedding new eugenic practices into reproductive health care defend the practice by saying these decisions are done by individuals and couples in private medical settings. These technologies are supposedly race-neutral, and the state has

little to say over who uses them or how. Next slide, please.

For those reasons, they look different from what most Americans think of when they hear the word "eugenics," which is government-led sterilization programs explicitly aimed at promoting race supremacy. Indeed, this was the aim of the American eugenics movement prior to the 1930s, and it was this version of eugenics that was imported into Germany by the Nazi regime.

The next two slides -- Angelica, if you could just go through the next two -- give reference to the importation of eugenics into Germany. And these are also in the reference sheet distributed for this talk. Next slide, please.

As racist state-led sterilization programs became associated with European fascism in the early 1930s, they began to fall out of favor in the United States. The American Eugenics Society, under the leadership of retired railroad magnate Osborn, began to promote a new vision of

eugenics, one aligned with the individual choice that characterizes today's genetic technologies. Next slide, please.

Osborn aimed to improve the gene pool by increasing births to the wealthy and educated, dressing births to the poor and uneducated, but this would be done at the individual level rather than by the state. It would be promoted by social norms that would encourage some types of people to have larger families and other types of people to have smaller families, and by financial incentives that would reward childbearing by the wealthy and educated while punishing it by the poor and uneducated. For example, he advocated tax income affect benefits. This would be affected by the widespread availability of birth control, which would provide the poor and uneducated the supposed freedom to avoid having large families. Osborn's vision of eugenics eschewed reference to race and national origin, with socioeconomic status serving as proxy. Next slide, please.

Osborn saw three new sciences as key for

his project. These were medical genetics, demography, and behavior genetics. Next slide, please.

In the 1950s, Osborn facilitated the addition of human genetics to the school curriculum and promoted the rise of genetic counseling. He and other geneticists expected once people became used to counseling to avoid genetic disease, they would become more used to counseling to avoid decrease in the so-called quality of the overall population. Next slide, please.

From the 1930s onward, he promoted and established the development of demography, the social science of human growth. This was the topic of my first book, *Building the Population Bomb.* In the 1960s, he looked to combine eugenics with behavioral genetics. Panofsky is the most well-known behavior geneticist. These books are in the reference list. Next slide, please.

Behavior genetics rests on the premise that DNA determines intelligence which determines socioeconomic status. These were

not new ideas when behavior genetics was founded at the end of the 1960s. They had been articulated a hundred years earlier by the founder of eugenics, Dalton, who contended socioeconomic status directly reflected intelligence which was a product of nature rather than nurture. Next slide, please.

Although intelligence testing originated in France for non-eugenic purposes, it was adapted into a tool of eugenics by American psychologists in the first decades of the 20th century. Next slide, please.

Eugenicists drew on the intelligence tests given to Army recruits in World War I to argue for restriction of immigration from eastern and southern Europe, and for sterilization laws passed in over 30 states prior to World War II. Next slide, please.

Despite decades of sociological research demonstrating that intelligence plays only a minor causal role in socioeconomic status, behavior geneticists of the mid-20th century took the second part of this equation for granted and focused their efforts on proving

the first, which is that intelligence is primarily a function of heredity. They did this with twin and adoption studies through which they estimated the heritability of IQ. Although scientists outside of behavior genetics have demonstrated repeatedly that heritability estimates are meaningless, behavior geneticists and their supporters continue to point to the supposed heritability of IQ to suggest socioeconomic inequality is natural and inevitable, or that it can only be ameliorated through selective breeding. Next slide, please.

As assisted reproductive technology developed in the last half of the 20th century, they were imbued with eugenics. Initially, doctors were the gatekeepers and would only assist those they believed worthy of reproducing. With IVF, they would select without input from the clients. The rise of sperm banking aimed to make the sperm of Nobel Laureates available to so-called qualified women, a eugenics effort. They also began to classify by the intelligence of their donors,

as eugenics became that influential. The market has now replaced the doctors as gatekeepers, excluding those who can't pay. Next slide, please.

As Osagie has demonstrated in his research, one of the primary members was of the Britain Eugenics Society, who fathered IVF. This has come closer to reality. Next slide, please.

The services offered take a new approach, genome-wide association studies. At the beginning of the 21st century, behavior geneticists began to search for genes that promoted intelligence, but continually came up short. Following the lead of medical genetics, they switched to genome-wide association studies. This approach requires enormous sample sizes, and behavior geneticists simply couldn't find enough people who had both been genotyped and had their intelligence tested. They therefore turned their focus to educational attainment as a proxy for intelligence. This allows for the construction of polygenic risk scores or

indices which summarize a person's propensity to experience the outcome in question, whether medical or behavioral. These work well at a population level but are not well suited to individual prediction. They are nonetheless what various companies use to guide selection. So selection on the basis of risk for intellectual disability, which is what was termed low educational attainment, doesn't just look like eugenics: it grew directly out of the early 20th century eugenics project. Next slide, please.

We can think about embryo selection at three levels. First, the use of polygenic scores to select for predicted intelligence, which is the most controversial of the three but not currently available. Second, the use of polygenic scores to select against disease risk, which is becoming more widely available. And third, the use of traditional pre-implantation genetic diagnosis to select against aneuploidy and single-gene disorders. This is the most common and least controversial. In the first case, scientists

have shown that this type of selection is unlikely to do much to increase intelligence. Its danger lies in the belief system that it supports, according to which DNA is the primary driver of intelligence and socioeconomic status. The popularity of these ideas threatens to divert resources from public education and social welfare to private genetic engineering. In the second case, attention to the genomic causes of complex diseases undercuts efforts to ameliorate their non-genomic causes, which play a much larger role. This is evident in efforts by the tobacco and chemical industries to attribute cancer to genetics in order to avoid regulation. In the third case, it can be helpful to approach traditional pre-implantation genetic diagnosis from a disability studies perspective. This framework suggests that many of the problems associated with aneuploidy or single-gene disorders result not from their physiological effects, but rather from a society that's organized in ways that make life difficult for

people who experience those physiological effects. In all three of these cases, the history of eugenics is helpful for thinking through what is at stake for society as a whole when new genetic technologies get combined with reproductive health care. Next slide, please.

Thank you. That's the end of my presentation, and I'm gonna turn it over to Lisa.

LISA DIVE: Thank you so much, Emily. That was SO interesting, and it provides really fantastic, rich historical context for what I'm going to talk about.

So, in my presentation, I'm going to outline how contemporary genetics -- and specifically, the practice of reproductive genetic carrier screening -- can draw on critiques related to eugenics to inform ethically defensible programs and practices. Next slide, please.

As is customary in Australia where I'm speaking from, I'd just like to briefly acknowledge that I'm speaking today from the

unceded land of the Tharawal people and express my respect for their ongoing custodianship of the lands and waters that we all enjoy around here, and extend that respect to the traditional owners of the many different lands on which we're all meeting today, and to their elders, past, present, and emerging. Next slide, please.

So today I'll briefly outline the eugenics critique as it's been leveled against practices such as genetic carrier screening. I'll consider various ways of responding to that critique. And finally I'll summarize with some key learnings from this analysis. And I should mention that the presentation today draws on a paper that was recently published by myself and my colleague Professor Ainsley Newson. So it's going to be a bit of a challenge to keep it brief, but I'll do my best, and there will be a link to the paper at the end. Next slide.

So first, let's just be clear and specific by what we mean by eugenics and how this applies to reproductive genetic carrier

screening. Next slide.

So, Emily has done a fantastic job of giving a very rich and detailed explanation of what we mean by eugenics. And so... it -- for our purpose, for my purposes, the term describes a range of policies and practices that aim to apply the science of heredity to promote desirable characteristics across a population. And, as Emily explained, the term is usually associated with the atrocities committed under the Nazi regime in Germany and in the early half of the 20th century in the U.S., but it also describes programs that took place in a range of other countries, including Australia and the UK.

Now, the eugenics programs of the early 20th century were widely condemned as abhorrent. But in our analysis of how this, um, is relevant to reproductive genetic carrier screening, we were interested in clarifying exactly what specific ethical wrongs these programs committed. And in analyzing various aspects of eugenics programs, we claim that there were two

fundamental ethical wrongs at their core. Firstly, programs like this held a very narrower view of what makes one person better or more desirable than another person, and this view was based in deeply discriminatory attitudes and reflected societal prejudices and intolerance for diversity. The second ethical wrong is that eugenics programs used methods that failed to respect all persons equally, and methods that we would find completely abhorrent today. They were often coercive and violated people's bodily autonomy -- methods like sterilization, incarceration, and worse.

Now, these were not the only things wrong. Notably, they were often based in dubious pseudoscience. But these were the two main wrongs we identified.

So, in response to these atrocities committed in the name of eugenics in the 20th century, as the discipline of eugenics evolved in the later part of the 20th century, it made great efforts to avoid association with those kinds of eugenics programs. In particular,

the discipline of genetic counseling came to incorporate an ethos of nondirectiveness, which was a center part of this effort to distance genetic counseling and clinical genetics from previous practices of eugenics. Although the practice of nondirectiveness has been the focus of some debate in recent decades, it still remains a legacy of eugenics and its influence in contemporary genetics. Next slide. Thank you.

So I'm going to assume that most people here know what genetic -- ah, know what carrier testing is: a genetic test to determine the likelihood that a person will have a child with a genetic condition. But for my purposes today, I'm specifically focusing on reproductive genetic carrier screening, which I've shortened to the acronym RGCS. The important features of programs like this, for my purposes, are that it involves offering carrier screening widely across a whole population -- in some cases, to anyone who wants it, or sometimes for anyone who can afford it -- and also that a program

like this screens for a large number of genetic conditions or variants. And our analysis is based on this kind of program in part because in Australia we're currently piloting a publicly funded RGCS program, which I can talk about later if people would like. And there's a link to the program, which is called Mackenzie's Mission. Next slide, please.

So, RGCS, particularly when offered widely across the population and when it screens for many different conditions, does have some elements in common with eugenics programs of the past. Programs like this have the capacity to influence which future people will be born. And as more governments around the world are becoming interested in offering reproductive genetic carrier screening to anyone in their jurisdiction who wants it, state sponsorship is an element that can prompt concerns about eugenics. Also, in screening for particular genetic conditions, RGCS can send an implied message that it would be undesirable to have a child with certain genetic conditions. And this is a value

judgment implied in the program. So even though we don't consider that contemporary RGCS commits the same ethical wrongs as eugenics programs of the 20th century, it has been criticized due to these common elements that it has. And this here is just an example of some negative media coverage which describe Mackenzie's Mission as a search and destroy mission for people who have genetic conditions. Next slide, please.

(clears throat) So how can we respond to this critique of reproductive genetic carrier screening? Next slide.

(coughs) As Emily mentioned in her presentation, too, the most common response to this critique that RGCS is a form of eugenics is to emphasize individual freedom of choice, and particularly at key decision points. In contemporary RGCS, no one is forced to participate. It's always optional, and informed consent is required. Similarly, if a couple does receive a result via RGCS that they have an increased chance of having a baby with a genetic condition, what they do with

that information is up to them. And typically, they'll be supported to ensure that they make the right reproductive choices for them that reflect their values. But we were -- we gave some thought to whether we thought this response was sufficient. And, um, next slide, please.

We don't think that emphasizing freedom of choice is enough, because this approach turns a blind eye to the social and normative context in which individual reproductive decisions are made. Simply by offering RGCS for certain conditions sends all sorts of messages to prospective parents, including the message that having a child with a condition like that would be undesirable, and also that good or responsible parents would take up or should take up the offer of screening. Participating in reproductive genetic carrier screening can start to be seen as a routine part of preconception or prenatal care, at least for parents who are considered good or responsible parents. And in this way, RGCS can actually undermine the freedom of

individual choices by the way that it's offered. Programs like this can also express discriminatory attitudes that devalue the lives of people who live with disability and difference. By screening for particular conditions, it sends a message that the life of a person with one of these conditions is less desirable or valuable than other lives. And emerging research is starting to show that such an attitude doesn't actually reflect the lived experience of many people who have genetic conditions or other disabilities, but their perspective tends not to be reflected in how programs are developed and how they're offered. Next slide. Thank you.

Responding to the eugenics critique involves recognizing that the way RGCS is offered, and the cumulative effect of many individual choices based on RGCS, together have the ability to influence societal norms. Furthermore, these norms provide the context in which individuals make their decisions. So when developing and implementing RGCS, we need to build in values like tolerance,

respect for diversity, et cetera, into the program itself. Next slide.

So, how can we do that? It's not an easy task, but we do have a few ideas that have come out of our research so far. Next slide.

Responding to the eugenics critique of reproductive genetic carrier screening involves paying attention to the social norms that provide the context for individual reproductive choices and recognizing the capacity of programs like RGCS to shift those norms. So we need to implement strategies to avoid routinization and responsiblization, and also consider how people with genetic conditions and other disabilities are represented in all aspects of the program. There are also a range of upstream strategies that can mitigate potentially inadvertently eugenic aspects of reproductive genetic carrier screening. Things like paying attention to how we as a society value people who live with disabilities. The kinds of things that Emily mentioned about the environments and the contexts of communities,

and how they, um... affect the degree of impairment experienced by people who live with disability and difference. Also making sure that the voices and perspectives of people who live with genetic conditions and their families are among those voices that inform program design and things like decision supports. And there are also specific programmatic elements that we can implement to ensure that people's choices about whether to participate in a genetic screening program are genuinely the best choices for them and align with their values. Next slide, please.

So this little summary slide just pulls together some of the things that we can do if we take the eugenics critique of reproductive genetic carrier screening seriously. I won't read it all out, but just basically to step through it briefly, it involves things like paying attention to the perspectives on disability and difference that the program reflects; making sure that gene selection is subject to careful scrutiny in a process that is robust and ethically defensible; ensuring

equity at various stages of the program -- so that includes things like access to screening, but also equitable access to reproductive options or interventions that might be available after screening; and also a coordinated approach to promote authentic choices based on genuine deliberation. Next slide.

So, thank you very much. This -- that's it from me now. And I look forward to the discussion.

OSAGIE OBASOGIE: Great. Well, thank you so much, Lisa -- both Lisa and Emily, for these wonderful presentations, and quite thought-provoking. I want to encourage -- (clears throat) Those of you who are attending to submit questions using the Q&A function at the bottom of your screen.

So, just to kick off this kind of broader conversation, one question that I had is a kind of extension of what both of you spoke about, which is kind of focusing on kind of the social and ethical implications of, of these approaches, and using kind of history and kind

of social norms as a context for understanding these kind of broader ethical implications. And my question is: How can you leverage this kind of broader historical and social understanding to inform public policy? So, kinda implicit in both of your presentations is this idea that we need some type of broader kind of public conversation or educational effort so that folks can really understand what's at stake, both in the contemporary moment and also in the context of what's happened in the past. And what does it mean to kind of translate these concerns into some type of kind of policy efforts so that there's a much more consistent application of these norms across various communities? So um, if either one of you want to respond to that, that'd be great.

LISA DIVE: Um, oh, I can jump in. I think Emily would probably have a lot to say in how we can learn from the past and understand the attitudes and practices that motivated the kinds of, um, eugenics programs of the past. But from my perspective as a,

sort of an ethicist looking at sort of drawing on that history, I think that a really important part is understanding the history in a really deep and robust way, and unpacking the kinds of the norms and the attitudes that motivated those kinds of programs. But then I think looking at also the kinds of practices and attitudes and how they came into play, and how we can do things differently now. So looking at things like the way that disability and people who live with disability have their perspectives represented, in the discussions, in policy discussions, in program design. Those kinds of things. So I would be interested to hear what Emily has to say from her perspective, as well.

EMILY KLANCHER MERCHANT: Thanks, Lisa. Um, yeah! Thanks for the question, Osagie.

So I think, you know, just at the very basic, these kinds of genetic technologies -- particularly embryo screening on the basis of polygenic scores -- there needs to be a lot more regulation of it. Currently, there is NO

regulation. In the United States, at least. And, so, you know, some scientists have begun to come out with, um... suggestions that polygenic embryo screening really won't have the effect that people who are selling it claim for it? But we definitely need more regulation of those claims.

But, taking -- you know, taking a step further... so, you know, I had said in my talk that behavior geneticists in particular call on the concept of heritability, or now on polygenic scores, to suggest that either socioeconomic inequalities are inevitable or that they can only be overcome with selective breeding. There's kind of a new approach to this in behavior genetics as well, which is people suggesting that... the kind of "reality" of genetic determination of socioeconomic status suggests what we actually need is more redistribution. So, the idea there being that, well, it's natural that there IS going to be inequality, but we need to redistribute so that there's just not as much distance between the socioeconomic

status of those at the bottom and those at the top.

And I think, you know, what really gets missed by that is all of the ways in which socioeconomic status is, is NOT a... product of genetics, but is a product of power relations? And that's what gets completely gutted! When we start to attribute social outcomes to, um, genetics.

And, so I think, you know, really, just kind of basic policy implications! Like, more power for labor relative to capital. More power for, you know... tenants rather than, you know, relative to landlords. And just, you know, these kind of really -- I wanna say "basic," but -- but policies that, um... would kind of promote more justice as a whole? That would leave less room, I think, for these scientific claims to get sold to the public.

OSAGIE OBASOGIE: Great. So we have one follow-up question from the participants on this issue of policy, and it's from Steve Joffe, who asks what might the content of such regulation be beyond analytic validity? And

specifically, would Dr. Merchant favor prohibiting embryo selection for certain indications, assuming technical accuracy?

EMILY KLANCHER MERCHANT: Um. That's a great question.

...it's, it's, ah... I, I suppose... well, I haven't thought through the, um, the implications of actual prohibition. But it's, it's hard for me to get to the point of technical accuracy? I think part of what's wrong with it is is -- sorry. Part of what's wrong with polygenic embryo screening IS that there's very little predictive power to them! You know. So, the polygenic index for educational attainment currently explains about 12% of the variance in educational attainment. For medical disorders, complex diseases, it's about the same! It can explain about maybe 10 to 15% of the variance. And, um. So, so it's even very hard to imagine a more predictive tool? And. But even if we COULD! You know, then I would get back to the disability studies perspective. And, um. You know, I'm blanking on, um... on

who -- which scholar I'm thinking of. It might be Adrienne Asch or Rosemary Garland Thompson, but the idea that if we allow for screening of some things but not others, then the things we allow for screening of will come to seem even more dire, even more socially unacceptable. And, so really the place to focus is less on, you know, prohibiting screening or prohibiting... termination of pregnancies for genetic reasons, but really on making the world a place where everyone can thrive regardless of their genetic endowment. Which will then make these kinds of screenings less, ah... less, um -- you know, enticing for people. Or, there'll be less of a market for them.

OSAGIE OBASOGIE: Right. I think that's an important point to keep in mind, in terms of how the ethical issues around these types of screenings is not simply about whether or not it's technically feasible or accurate, but why we want to do this in the first place. And I think that's important to just keep on the table. I think we often have -- so much of

this conversation can often veer towards, well, once the science is accurate, then it would be appropriate to do XYZ. And I think a lot of your work and a lot of Lisa's work is trying to ask us to consider why we even want to make these type of interventions to begin with, and whether -- how the desire to do so is steeped in this part of history and context that is often informed by eugenic logic and eugenic thinking.

LISA DIVE: Mm! Can I just jump in there and add? I think it's quite interesting the difference in different countries, as well. Because in America, where -- in the U.S., where you have -- it's my understanding is it's mostly a commercial endeavor? Things like preconceptional, the sort of carrier screening, is offered by private companies. And so it's a consumer product. Whereas in Australia, we're looking at it as government-provided, offered from the government. So that is -- that process I'm aware of in a few countries in Europe, as well. So when screening is offered for a condition

by the government, then that lends weight to that idea that living with a condition like that is undesirable. And something that... parents might have an interest in avoiding. And so it's very normatively laden, even just offering screening for particular conditions. So. And then if you have private companies as well, they have that very emotive marketing that goes along with it that reinforces those messages in a different kind of way than the government kind of sponsorship. So.

OSAGIE OBASOGIE: Right. Great! So, thank you! So we have a question from Robert, who asks -- who says, there is a valid argument about not devaluing people with disabilities or differences, but he doesn't hear anything about the other end of the spectrum -- that is, helping parents not have children with certain debilitating or lethal childhood diseases. Would either of you like to respond to that?

LISA DIVE: Um, I'm happy to, to jump in, and hand over to Emily if she has anything to add.

Something that we're considering in our

research at the moment is this idea of severity. Because one way of responding to the eugenics critique that has been leveled against programs like our program -- our current pilot project, Mackenzie's Mission -- is to say that, yes, we don't want to devalue the lives of people who live with disability and difference, but some conditions -- and the example that is often given in our program is spinal muscular atrophy type I, which is a debilitating degenerative condition which, babies who are born with that condition rarely make it to their first birthday. And our program is named after a baby who was born with this condition, and she died when she was 7 months old, tragically. So, for her family and for families who have babies with conditions like spinal muscular atrophy type I, avoiding the suffering and the sadness that is involved with that kind of experience is something that motivates programs like reproductive genetic carrier screening. And that is quite valid to avoid that kind of suffering. And so

sometimes, a way of responding to the eugenics critique is to say that we'll only screen for very severe conditions. But then when we start to, when we start to take into account, ah... sorry, I just saw an interesting question flash up and lost my train of thought. The severity of genetic conditions, the way they're described, has a very subjective aspect to it. And so it becomes very hard to draw the line in what is severe enough to warrant screening for it. And then there's also this other flipside that if you limit screening to severe conditions, then it IS something that is very much about avoiding the birth of particular types of people, which becomes a very problematic normative stance, as well. So. Emily, I don't know if you had anything further to add on that. But it is something that we're thinking about a lot at the moment.

EMILY KLANCHER MERCHANT: Yeah. So, you know, there are currently a lot of technologies available for prospective parents to avoid conditions -- all kinds of

genetic conditions. There's the reproductive carrier screening that Lisa talked about; there's the pre-implantation genetic diagnosis that I talked about. These are, these are available! There's nothing currently preventing parents from using them. So I don't think there's a danger that parents won't be allowed to make these choices. I think, you know, what we need is kind of more... more support for people who DO live with these conditions? And more education for prospective parents so that, you know, kind of... the point that Lisa was making! So that it can be an actual choice.

OSAGIE OBASOGIE: Great. Thank you. Let's see. So, we have a question from Stacey Pereira, who asks: I'm curious about your thoughts on how you support quote-unquote "authentic" decision-making processes, and how do we know the difference between authentic and inauthentic decisions, and who decides? And I think we can combine that with another question asked about how do we ensure these decisions are made in a way that doesn't

necessarily involve some kind of state coercion?

LISA DIVE: Yeah, that's a great question. And it's something which is -- um, some of my colleagues in Mackenzie's Mission would be able to speak to this in a lot greater depth? But we've got a very, um, a very wide multidisciplinary team working on these kinds of issues, and we've got -- so, genetic counselors have worked with others, including patient groups, patient advocacy groups for particular genetic conditions, to develop online decision supports. And other, other ways, other sort of, um... information packages and videos and things like that, to help prospective parents who are considering screening think about what kind of result they might get and what it might mean for them, what kind of choices they might make based on a certain result from a carrier screening program. So I think it's important to have a process that prompts value reflection, and that gives as rich and comprehensive an understanding of what it's like to live with

different genetic conditions that are screened for. One that's not limited to the medical perspective but incorporates patient perspectives and family perspectives and so on.

And so, as -- there are publications coming out of Mackenzie's Mission about the decision support that was developed for this particular program. And then our research is informing the further evolution of things like that. So I think it's important to have diverse perspectives incorporated and values reflection, are some of the key points there.

EMILY KLANCHER MERCHANT: And I think, you know, we might also think about coercion that's NOT just coming from the state? Particularly in a society like the United States, where we don't have national health care. Insurance companies, you know, have the power to coerce. Currently we have protections against, against preexisting conditions! But it's very easy to imagine a world where, you know, if a parent does do a screening, finds that the child will have a

certain disorder, and decides to continue the pregnancy anyway, that that disorder will be considered a preexisting condition and the child might not have any kind of medical coverage. And so we can see coercion coming from the private sector as well. And I think these are both things that we need to guard against. And another danger of kind of private health care is that, you know, some people can afford screenings and other people can't. And we can think of that also as a type of eugenics! Right, if certain people have better access to technologies that will help them have children who survive longer, and others don't have that access, that could also be considered a form of eugenics.

OSAGIE OBASOGIE: Great. Thank you! So a question from Marci. She asks: How do the eugenic dynamics and concerns you each have examined in embryo screening and carrier screening overlap with or differ from eugenic concerns about heritable genome editing? Are debates about heritable genome editing adequately considering its eugenic

implications?

LISA DIVE: Oo, that is super interesting! I think there's a rich avenue of sort of analysis there. It's not something that I've given a great deal of thought to yet, but I think it's a really important area to explore.

OSAGIE OBASOGIE: Mm-hmm.

EMILY KLANCHER MERCHANT: Yeah. It's, um. You know, it's something that's very far away in terms of polygenic conditions? Because -- so, for example, with educational attainment, there are SO many snips involved in that polygenic index that you would, you would not be able to edit, ah, an embryo for that. But at least! (laughing) It would be a really bad idea. And I think, I think everyone involved knows it.

But yeah. I think, you know, with heritable... heritable genetic editing, then, you know, you've got eugenics kind of right on the face of it. It's what would be inherited from generation to generation. And it, um, certainly deserves a lot of attention and

discussion.

OSAGIE OBASOGIE: Great. Thank you. So we have a question, we have a question from Uzra Aziz. They ask: As a current genetic counseling student, I wonder what we can do to make the history of eugenics and policy an integral part of training programs? This is for me a very interesting question. I have a couple of graduate students who are studying these programs to understand how they are kind of grappling with this history of eugenics, and the particularly questionable histories around genetic counseling. So I think it's an important question to see how the reemergence of some of these genetic counseling programs are kind of exposing this past to contemporary students to make sure that folks are knowledgeable. But do either of you have any kind of thoughts or ideas on how to make sure that genetic counseling training programs thoughtfully engage this past so that the next generation of professionals can do their work in a thoughtful and ethical way?

LISA DIVE: Yeah. Absolutely, yeah.

I'm actually -- I'm involved in, um, a genetic counseling program in Sydney here at the University of Technology, Sydney. And that program has explicitly woven ethics into many of their different subjects, rather than having it as a stand-alone sort of separate block. And it does a fantastic job -- there's a whole subject on population genomics and the history of eugenics is covered in that topic. And students are really encouraged to reflect on that history and on things like the origin of this ethos of nondirectiveness, which I think is such an interesting aspect of the profession of genetic counseling, because it's so... it, in many ways, it was a response to the history of eugenics, this idea that genetic counselors and medical geneticists should be just providing the information and allowing people to make their own choices. But it's, there's some really interesting literature in recent decades about the extent to which any kind of health advice can really be value-neutral and things like that.

But I think -- I've seen a couple of

comments flash up in the chat that this kind of content IS integrated in many genetic counseling programs. And from my experience, certainly I would affirm that.

EMILY KLANCHER MERCHANT: And as a historian, you know, I think it's very important to teach about the history of eugenics! Certainly -- certainly to genetic counseling students, but really to all students in the life sciences and medicine. But I think it's also important to emphasize that eugenics is not just history? It's not only in the past? And that these training programs also need to include disability studies. And maybe even... have some kind of, ah, interaction with the disability rights movement. And I think that can help us -- help people in that field be aware of, um, ways in which eugenics is still with us today.

LISA DIVE: Mm. Absolutely, yes. I'd agree with that.

OSAGIE OBASOGIE: Mm. Great. So we have another question from Alexandra Stern.

And she asks -- (clears throat) Excuse me -- how do the panelists assess how COVID is reshaping, and perhaps underscoring, eugenic biases in terms of who is healthy and who deserves care? Case in point is with the CDC director's recent comments on the fact that most people dying have four or more co-morbidities, and quote-unquote "that's encouraging." How is the COVID context reshaping your research or research concerns? I think this is a fascinating question. One of the things that I found quite disturbing was early in the, during the pandemic in 2020, you know, there was a lot of concern for the first couple months. And when we first -- when we started to see some of the initial data, that the vast majority of people who were hospitalized and dying were poor people of color and people who were elderly, that really started the conversation in the United States about how we need to kind of move past COVID and continue our lives. Because those people -- the implicit conversation from that was those people, the people who are suffering

the most are people who are, in a sense, disposable or not essential to society. And we can't really understand that phenomenon without a deeper history of eugenics, and how that eugenic logic allows for those type of conclusions to be made. So I think this is a fascinating question, and would like to hear any thoughts that you all might have.

EMILY KLANCHER MERCHANT: Um, yeah. So this is something that's been on my mind a lot, since that comment was made by, ah, by the director of the CDC. Particularly -- I mean, I am someone who has conditions that would make, make COVID pretty... um, dangerous for me. And, um... yeah! And I think -- you know, what I HOPE is that... because COVID is such a... something that we're all experiencing right now? You know, I hope that'll WILL make people more, MORE aware of these kind of eugenic policies! That really -- the policy of the government to, you know, to not mandate... And I should say, governments at various levels! To not mandate vaccines, or masking in certain

places. These really do have the effect of... disproportionately harming people who are already, have co-morbidities, people with disabilities. And, you know, I've seen people on Twitter referring to COVID, that COVID is going to be a mass disabling event due to long COVID. So, with everybody -- you know, so many people are getting COVID right now. There's... you know, going to be knock-on effects. Many more people are going to be experiencing chronic health conditions. You know, MAYBE there will be a chance for that kind of large-scale public awareness to change policy? In terms of, in terms of health care at the very least. But, you know, I think COVID has -- and our government at least, our government's response to COVID... has really just, you know, reiterated the way in which so many policies, on so many different levels, enact eugenics. You know, it's really, it's NOT just about the types of things that Lisa and I have been talking about. There are all kinds of policies that, you know, promote the wellbeing and the reproduction of certain

types of people over others.

LISA DIVE: Mm. Yeah. I think, um -- I would echo what you just said, Emily. And I think it just, for me, that comment from the CDC director, it just reinforces that idea -- like, what we identified as one of the central things that was, that is so ethically problematic with eugenics, is that it presumes a different, differential valuing of different lives in our society. So I think with COVID, it really has thrown into really sharp relief the way that we, as societies... value the more vulnerable people in our communities. And I think it's sort of brought that to light, in a really uncomfortable way?

OSAGIE OBASOGIE: Mm-hmm. Great. Ah, thank you for that. And we have a question from Carolyn Chapman, who asks: What does -- or what do you all think about the hypothesis of the new book *Genetic Lottery*, which is that we should not shy away from behavioral or IQ genetics, but instead use them to help the genetically vulnerable, so to speak.

EMILY KLANCHER MERCHANT: Um, I've already said a couple of things about that, so I'll let Lisa go first, and then I can jump in.

LISA DIVE: Um. Okay, um -- sorry, could I just have the question again? I didn't, um...

OSAGIE OBASOGIE: Sure. So it's a reference to the new book --

LISA DIVE: Behavioral genetics?

OSAGIE OBASOGIE: Yeah. So basically, the proposition that instead of kind of being cautious or careful around these type of behavioral genetic interventions that, they may present an opportunity to kind of redistribute certain talents to folks who do not have them. Or, if not talents, health abilities, things of that nature.

LISA DIVE: I don't know, I mean, I'm not probably as well qualified as Emily to respond to this, because I'm not that familiar with the discipline of behavioral genetics or that kind of, that, um... I guess, that line of thinking. But I think, um... it just seems to be grounded in not a very scientific understanding of the

way that genetics actually works? You know, just from my experience of trying to understand what genetic variants even mean for the health of a person? In terms of particular genetic conditions. It's SO complex, and so difficult to predict anything with any kind of accuracy. Even for well understood, well described conditions! There's enormous variability. And then to attribute, when you start incorporating polygenic risk scores and attributing things, it's just SO deeply determined by socioeconomic... you know, by your post code, your family, your education, your -- all those kinds of social determinants of health. And... all that kind of thing. I think it's just, there's a lot of complexity and a lot of problems with that kind of approach.

EMILY KLANCHER MERCHANT: Yeah, and I can just pile on that a little bit. So, I, with some colleagues at UC Davis, I wrote a review of the book, and it's in the LA Review of books. The lead author is Hen, if you want to look for that. But we were very critical of that

argument. So, the book kind of posits a world in which everything else is equal, except genetics? And in that kind of world, I think it could make sense to redistribute on the basis of genetic endowment? In our current world, you know, there's just so much else going on, and that the vast majority of socioeconomic inequality -- which is Harden's main target there -- is NOT genetic. And to focus on genetics as either a predictor or a cause of inequality is just really misleading and just undercuts attention to power and who has it and who doesn't. And, you know, she recommends redistributing resources, but not redistributing power. And without a redistribution of power, we're not gonna have a lasting redistribution of resources.

OSAGIE OBASOGIE: Well, thank you so much. We're just about out of time, but I want to take a moment to thank both Emily Merchant and Lisa Diva for their comments and their engagement. This has been a fascinating conversation. And I hope that the audience also enjoyed it. And I will turn things back

over to Mildred Cho.

MILDRED CHO: Hi. Thank you, Osagie, for moderating those fabulous questions. And thanks to the audience for providing all those questions. We do have a little time after this in our post-forum discussion. So, we hope you can join us for that. The link is in the chat. And that's immediately following this. And we also hope to see you in February for our next ELSI Friday Forum, which is called "Genomic Imaginaries: Sparking Dialogue between ELSI and Literary Studies," between Lesley Larkin and Lara Choksey, and moderated by Dr. Rebecca Wilbanks. Also, you'll receive a post-event survey. I encourage you to complete this, as our organizing committee takes your comments and suggestions seriously. I wish you all a wonderful weekend. Thank you.

So I hope you all can find the, um, the link in the chat to the other forum. Where it says "post-forum discussion link." And if you click on that, it will take you to, ah... a different Zoom room.

LISA DIVE: I think I need to jump out. Thank you. So do we hop out of this Zoom now? Okay.

MILDRED CHO: Yes.