

Interest Group 8: Exploring Data Justice, Structural Racism in the Context of COVID & Climate Change

Shiriki Kumanyika: Welcome. It's my pleasure to welcome both the members of the National Academy of Medicine Interest Group 8, which focuses on the health of populations and health disparities and to also welcome the members of the general public, who have chosen to attend our session. We know there's a lot of competition for sessions during this slot, and we're really pleased that you've joined us.

I'm Shiriki Kumanyika, professor at Drexel University School of Public Health and the chair of this interest group, and I have the pleasure of working with Dr Karen Emmons, a professor at the Harvard School of Public Health, as the vice-chair of this interest group.

This is also my opportunity to acknowledge and thank those who have helped to plan this program. Besides, Dr Emmons and myself, the other interest group members or on the planning committee are Drs Nancy Adler, Mary Bassett, Paula Braveman, and Graham Colditz. We are also very appreciative of the continuing support we get throughout the year from the NAM Senior Membership Associate, Mr Jamal Samuel.

Our interest group themes are linked to the overall NAM meeting themes. Both this year and last year, the themes have related to aspects of the COVID-19 pandemic and climate change as major threats to human health. Our 2020 program, which was held jointly with the Interest Group on Health Policy and Healthcare Systems, focused on what we could learn from the intersection of COVID-19 and racism, motivated by the emerging racial justice movement, and we wanted to see what we could learn to foster positive solutions going forward.

As indicated on this title slide, this year we're going to delve into some really critical issues that are largely underappreciated, if not unappreciated, related to data and data justice as a racial justice issue that relates to both COVID-19 and climate change.

The program agenda is shown here. We will have three speakers, three panelists, and a moderated discussion until about 3:15PM. Dr Emmons will then close the public session and the webcast will end. The interest group members are invited and asked to remain on for a short debrief, a follow-up session for members only.

Now, I would like to introduce Dr Graham Colditz who's going to be our moderator, and he will introduce and then moderate the panel.

Dr Colditz is at the Washington University in St Louis where he is the Niess-Gain Professor and Chief Division of Public Health Sciences in the Department of Surgery. He's also Program Director of the Master Population Health Sciences Degree Program, and Associate Director for Prevention and Control at the Alvin J. Siteman Cancer Center.

I'll turn this over now to you, Dr Colditz, for our really exciting session.

Graham Colditz: Thank you, Shiriki, and welcome, too, everyone.

I will, as you said, briefly give some context and introduce our speakers. In a way, we've all been exposed to many lessons from the pandemic. Clearly, we've pulled the curtain back on many structural factors in a way that the general public has seen this and understood, I hope, in more detail than before, but it's also reinforced the need for a focus on population health in a way that has been underfunded and often ignored.

The climate change crisis comes hand in hand with this, and while many are expecting that we'll emerge from COVID. The climate issues are not going to go away. In a really fundamental way, this makes the topic here today even more important. The climate crisis has repeated insults, if you will, on low-income and marginalized communities in the US and around the world and really motivates equal importance on data, data issues, and how we use it.

We have many cities and states not doing a good job on collecting data, using data, access to data, evaluating inequality. So we're set with policies being made on incomplete and inaccurate data that affects, in fact, all of us. When such data is collected, it's not always made available in ways that can support strong health measures and policies. We could play a video of some of the issues that have arisen over the last 2 years. Of course, when attention is not paid to the ways that data can reinforce existing inequalities and races' structures were cut, we cannot improve the health of all but, in fact, do more harm and reinforce the inequities we have already. That's certainly been true with the pandemic, and as I said, the climate change that's continuing will mean that these issues are sustained in the years ahead.

Our panel today is going to address all these issues in the short time we have. How data can be used in ways that reflect poor quality and inaccurate science and can be harmful, and how we must attend to the issues of data related to racialized groups as a core scientific principle. We're also going to hear about approaches to use data more effectively and in collaboration with the communities that experience the inequities and the harm related to both the pandemic and climate change. It's imperative our approaches to both crises facing the whole world at this moment, the pandemic and climate change, engage communities that are most affected.

We hope the panel today will shine a bright light on the factors that are foundational to scientifically accurate and ethical use of data for the benefit of the population. We look forward to the discussion that follows the presentations that Shiriki just pointed to.

We'll begin with Dr Krieger from Harvard School of Public Health addressing health justice, embodied truths, and the two-edged sword of data; structural problems require structural solutions.

She's followed by Drs Davis and Waters from Washington University School of Medicine addressing race in COVID risk prediction models; how are we using data?

And they are followed by Dr Newell from Food and Agriculture Institute in the University of Fraser Valley, British Columbia, again bringing another perspective of the data use and engagement. His topic COVID-19, climate change, and integrated planning for healthy communities.

With that, I will turn it over to Dr Krieger. Nancy?

Nancy Krieger (she/hers): Thank you very much.

Thank you for including me today. My talk, Health Justice, Embodied Truths, and the Two-Edged Sword of Data: Structural Problems Require Structural Solutions and begin by acknowledging that as a US person in Boston, Massachusetts, that I am on Indigenous lands and pay heed to critical Indigenous thinking. Also, at a time of continued reckonings, structural racism, past and present plus continue challenges to building a multiracial democracy, all of which are profoundly intertwined with COVID-19.

In my 12 minutes I'll offer a brief, conceptual introduction for you about Ecosocial Theory, followed by some specific empirical examples involving COVID-19. Forever mindful that we live in a planet of extraordinary beautiful beauty and complexity, one which people can either enhance for the good of all or to strive for the profit of a few. I will close by affirming the necessity of critical science for the people's health. I've also prepared a suggested reading list with relevant references that can be available to you by the organizers of the symposium.

My starting point is to affirm that antiracist and anti-essential sciences are essential. The point of analyzing scientifically how racism harms health is not to prove that injustice is wrong, since it is by definition. Nor is the point to do quote/unquote "politically correct" science; rather, the point is to do correct science to generate the realities and causes of health inequities, many differences in distribution of health outcomes across social groups that are unjust, avoidable, and in principle, preventable.

Nor is work on racism and health a quote/unquote "niche" issue. In the US, persons of color comprise 40% of our population. Evidence abounds as to the ubiquity of self-reported experiences of racial discrimination, also the pervasiveness of structural racism and the harms these cause to individual and community health. Stated in another way, in racialized societies, good luck finding health outcomes that don't manifest as racialized health inequities.

Indeed, galvanized by the past 2 years, relentless exposes of and organizing to confront social and health and justice, both the NIH and CDC have finally explicitly stated that structural racism is real and a serious threat to the public's health, and are investing resources to address these issues. Mind you, these unprecedented statements should not be controversial, as these two facts have long been self-evident to and documented by those not protected by racial privilege, and also evident to any serious scholar of the people's health.

But, of course, to comprehend, analyze, and guide action to rectify these facts requires theory. On this slide, I show the overall framework of the ecosocial theory of disease distribution, which I first proposed in 1994 and have elaborated since, and I also show its direct application to analysis of racism and health. Concerned with levels, pathways of power, and also time in relation to both individual life course and historical generation because ecosocial theory seeks to explain population distributions of health and health inequities. A central focus is on embodiment, referring to how we literally incorporate biologically our societal and ecological context, thereby producing population patterns of health and health inequities. This theory clarifies there are many pathways by which structural racism harms health, including but not limited to economic and social deprivation; excess exposure to toxins, hazards, and pathogens; social trauma; health-harming responses to discrimination; targeted marketing of harmful commodities; inadequate medical care; about ecosystem degradation and also alienation from the land, especially, but not only for Indigenous peoples.

The ecosocial constructs of agency and accountability further clarify that racism not quote/unquote "race" is causally what's relevant and is diametrically opposed to the dominant view, which draws the

arrows from quote/unquote “race” to racial differences in health status and culture, seeing the problem is alleged biological and cultural inferiority rather than White supremacy and the privations imposed by the privileged to protect their wealth and status. Reckoning with health inequities requires reckoning with embodied histories and structural racism.

A rigorous and anti-essential science, and thus an antiracist science likewise requires reckoning with who wields a two-edged sword of data. A crucial first point is that data, contrary to its etymology, is never a given despite being the past participle of the Latin verb *dare*, “to give.” Data are always produced by people, revealing what they observe, fail to see, or suppress. The key sticking point to remember is that privilege is always defined in part by who and what you can afford to ignore. Another is that essentialist, racist assumptions have been contested ever since they were first espoused, meaning the excuse that, “that’s just the way people thought back then” was not ever and is never acceptable.

Accordingly, one always must ask, who produces and controls the data? To what end, and engaging with what history? For the US histories of the contested production and use of racialized data extend back to the origins of the slave republic and settler-colonial nation. Mindful of time limits, I’ll simply flag these data were first produced and used in the 18th century CE by the enfranchised minority of White men with property to entrench injustice, to characterize who was enslaved versus free, and which Indigenous tribes and nations were vs were not under colonial and then federal jurisdiction. Their use became increasingly contested in the 19th century CE as abolitionists, including the first generation of credentialed African American physicians, began to contextualize racialized data to challenge slavery and challenge its many supporters, including proponents of scientific racism.

Next, for the 20th century CE context, stations involving use of racialized data to oppose or else support the Jim Crow regime of legal racial segregation backed by terror. The same could be said for eugenics, an ideology upheld by the US Supreme Court and leading US scientists, university presidents, politicians, and more, one which led to the passage of eugenics sterilization laws in 32 US states, and also the Immigration Restriction Acts of 1824 and 1927.

Then, in the wake of major legislation, one in 1965 by social movements that afforded new protection of civil rights and expanded immigration, uses of official government data on race and ethnicity shifted to providing evidence of injustice as opposed to justifying it. However, the successful Civil Rights strategy of using racialized data to demonstrate the existence of what was called quote/unquote “statistical discrimination” or quote/unquote “disparate impact” sparked, unsurprisingly, a Conservative backlash, leading to two types of resistance. One was to try to suppress collection or reporting of racial ethnic data; the other, in legal cases, was to require evidence of motivation, not just disparate impact.

Hence the two-edged sword of racialized data. In societies with deep histories of structural racism, not using racial ethnic data that is a quote/unquote “colorblind” approach leads to the problem of “no data, no problem” and the denial of an inability to prove that problems exist. That’s edge one of the sword.

Edge two is that problematic data, whether wrongly conceived, wrongly used, or both, can also be a big problem. Meanwhile, keep in mind the point, the actual point: what are the data needed to secure health justice?

Let me now share two illustrations of how the two-edged sword of data can cut deeply, causing deep harm for what I presented at the first meeting of Federal COVID-19 Health Equity Task Force back in February 26 this year.

First edge number one: “no data no problem.” During the first terrible months of the pandemic in the US, you could barely find any government COVID-19 data stratified by race/ethnicity, despite this being a standard variable for just about every other health outcome. Instead, in these early periods that were crucial for understanding and altering the course of this pandemic, data journalists led the way in piecing together the evidence, illuminating both data gaps for, and also the greater burdens among nations of color.

In response to public outcry, on June 4, EU regulations mandated reporting racial ethnic data by no later than August 1. However, on September 16, my team and I checked the CDC website and found that racial ethnic data were still missing for 43% of the COVID-19 cases added between August 28 and September 16. We checked again in early February this year, and for cases reported between December 2, 2020, and February 3, 2021, fully 33% were still missing these data. Worse, on February 1, CDC reported that racial/ethnic data were missing for 48.1% of persons vaccinated against COVID in the first month of the rollout, which was December 14 to January 14. But only point 0.1% and 3% were missing data respectively on age and sex. And despite continued outcry, as of October 11, last week, these racial ethnic data remain missing for 39% of persons who have received the first shot and 35% of those fully vaccinated.

That said, the CDC COVID-19 health equity data has begun to improve noticeably since this past spring under the new administration, and includes more, but not sufficient, data on economic, occupational, community, and other contextual data.

Moving on to edge two. The initial response of the CDC to the outcry about missing racial/ethnic data was to focus on proportions, not rates, comparing the racial/ethnic composition of COVID-19 deaths versus that of the total population. But the data made no sense because, contrary to the reports coming from the field, the CDC data indicated that White non-Hispanics were overrepresented and Black Americans were underrepresented among the COVID-19 deaths. Working with some doctoral students to figure out what went awry, we realized that the CDC had committed a classic type III error, right answer to the wrong question, as we demonstrated in our publication last July.

In brief the CDC weighted—to check the July last year before this one—in brief CDC weighted the denominators for the US counties by the percent of total COVID-19 deaths occurring in that county within the state. Given who was hardest hit by COVID-19, the net effect was to deflate the denominators for the White non-Hispanic population and inflate the denominators for the populations of color, respectively inflating and deflating the risks. CDC stated rationale was that the racial/ethnic composition of places initially hit hard by COVID-19 differed from that of areas hit less hard, and they sought to quote/unquote “correct for this” by weighting.

To ask and answer the question, how does racial/ethnic risk for COVID-19 mortality vary apart from how racialized segregation affects who lives where is to ask and answer entirely the wrong question. By treating place and the lived experiences and impacts of residential segregation as nuisance factors, to be quote/unquote “corrected” for by weighting, the CDC reached the entirely wrong conclusion.

Responding to these criticisms the CDC under the new administration has fixed its approaches, as you can see on the slide, with the data now showing the percentage of COVID-19 cases, death, so on, the percentage of the US population, by racial ethnic group, making it easy to spot the difference between the two.

Were these data problems inevitable? No. As the pandemic got underway, plenty of studies by my team and others reported more or less than real time COVID-19 outcomes by diverse social metrics including racialized economic segregation at the county, city, town, ZIP Code, and even Census-tract levels.

At the first meeting of the Federal Covid-19 Health Equity Task Force, again, this past February, I recommended that COVID-19 data should first always reveal racialized economic health inequities in real time, and second, always be presented jointly by racialized and economic group, along with age and gender at a minimum. That such data are increasingly showing up at the CDC website now means it could have been done all along.

At this meeting, I also shared suggestions regarding data for an article I published last April, arguing the structural problems require structural solutions; goodwill is not enough. My proposal involves a feasible two-part, enforceable institutional mandate. Part one is that all US health data sets and research projects supported by government funds must explicitly explain and justify their conceptualization of racialized groups and the metrics to use to categorize them. Part two is that any individual-level health data by membership in racialized groups must also be analyzed in relation to relevant data about racialized societal inequities, and there is a slew of spectral measures available.

There is precedent for such mandates. Consider only the 2014 NIH mandate that all grants must address “sex as a biological variable,” even if this mandate continues to remain silent about gender. Failure to comply does affect the grant score; this can be done. Or for a more dramatic carrot-and-stick example, consider the case of desegregating US hospitals. In 11 short months between passage of the Civil Rights Act of 1964 and implementation of Medicare in 1965, whose funds could only go to desegregated facilities, the AMA and the vast majority of US hospitals finally ceased supporting segregation and swiftly desegregated.

Also needed is equity-oriented work on data governance. That is, who has input into making the decisions about which data are required, informed by the tandem expertise of health equity researchers and other members of communities whose data are at stake, affording the expertise of lived experience. Continuing with the status quo is not acceptable.

In closing, we live and die embodied, and the embodied truths of injustice are revealed through population patterns of health inequities. It is essential to use antiracist and anti-essentialist science to confront the two-edged sword of data so that we can correctly monitor and analyze inequitable burdens and exposures in adverse health outcomes. Only with such a embodied truths backed up by the possibilities of lawsuits, legal accountability, and social movements organizing for social justice and changes in policies and regulations, do we stand any hope of making any headway on the twin tasks of protecting the people's health and advancing health equity.

And, no matter where we reside, let us do our work informed by history and envisioned premise of social justice and human rights, along with deep recognition of our interconnection with a dependence on our wondrous and threatened planet.

Thank you.

Graham Colditz: Thank you, Nancy. Let's move to the next team presentation. We have Drs Davis and Waters. Thanks.

Erika Waters: Thank you all so much for joining us here on this Sunday afternoon. Today we are going to talk about race in the context of COVID risk prediction models. Next slide please.

This work is based on an article we published in the *Journal Of The National Cancer Institute* several months ago about the inappropriate use of race and the exclusion of social determinants of health in cancer risk prediction models. Next slide please.

Let's just start out first though by talking very briefly about clinical risk prediction models more broadly. These models generally predict the likelihood of different health outcomes, including the likelihood of developing an illness, the likelihood of surviving an illness, that a clinical condition will progress to a more serious stage, mortality and responsiveness to defense therapeutics. Next slide please.

The prominence of clinical risk prediction models has increased as biomedicine has sought to develop personalized or precision medicine approaches. These approaches tailor therapy based on an individual patient's needs. Next slide please.

Risk-stratified mammography screening is one example. It seeks to maximize the benefits and minimize the harms of mammography screening by having individuals at high risk undergo more intensive screening and individuals at low risk undergo less intensive screening. The United States Preventive Task Force recommendations for mammography screening for breast cancer is one example of recommendations that combine both risk-stratified screening and risk prediction models. Next slide.

So how is race addressing cancer risk prediction models? Well, kind of echoing what Dr Krieger said a few minutes ago, oftentimes if race is identified as a predictor in a cancer risk prediction model, it is corrected away. A statistical correction is applied to bring the estimate up to the population level. The problem with this is that these corrections essentialize rates. The idea of racial essentialism is that these are fixed, immutable characteristics that apply to all members of a group. Essentializing race assumes clear distinctions between Black and White, when that has never been the case in the US. Essentializing race, also, that does not distinguish among people of different demographic origins who may have similar skin tones. So, for example, a Black person from Brazil has life experiences that are very different from a Black person from the United States whose family has been in states for generations. Next slide please.

And I'm going to turn it over to—sorry—what kinds of harm can these corrections do? We get at the issue of that Dr Krieger said earlier about not performing correct science. So, once we start, including these corrections, we risk inhibiting health disparities research and health equity efforts. For example, the EGFR metric for kidney function can make it appear as though Black people's kidneys are functioning better than they actually are in real life. We have several other examples here. Next slide please.

And how his race—excuse me—adding to these complications is that there's seldom an explanation that race is a social construct, that there is any biologically plausible mechanism driving the effect, and there is seldom an explanation of social structure factors that produce these underlying correlations. Next slide.

And with that, I'll turn it over to Dr Davis.

Kia Davis: Thank you, Dr Waters.

So similarly, COVID risk prediction models were quickly developed to identify who had increased risk of being affected with Coronavirus or diagnosed with COVID-19 to identify at-risk populations. They also help predict prognosis of disease, severe disease, who might need any ICU admission, any need for ventilators or intubation to inform treatment but also to help allocate dwindling resources.

In a review of 236 prediction models, we learned that the earlier models mostly excluded race all together. So, as the review here concludes, that the most frequent types of predictors that were utilized were vital signs, age, comorbidities, and image features. While these earlier models didn't essentialize race, ignoring race—given the racism, given the complex intersection of COVID-19 and structural racism—is not best practices either.

Subsequent models did begin to utilize race, although those either did not provide any adequate context of what race represented in the models, or they suggested biological differences related to susceptibility that were responsible for observed racial differences in COVID-19 outcomes.

We know there's a multilevel context that drives exposure, susceptibility, and treatment. And so here on the left, you see an image of CDC's version of the social, ecological model, and this is mainly meant to be an instructive to understand the different exposures at multiple levels. And so, mischaracterizing the causes of disease and excluding this context harms and often leads to solutions that will not fully address the public health challenge at hand. Here's an example that shows multiple factors on the right that are consequences of racism and also associated with COVID-19 across multiple levels. At the individual level, we have comorbidities that might impact exposure, susceptibility and treatment, additional medical mistrust, and lack of mask-wearing—again, things that are a result of structural racism but show up in individual folks. And then at the interpersonal, or relationship level, we have poor patient-provider communication or lack of a usual source of care that also complicates COVID-19 diagnosis and treatment. At community levels, it has, as has been discussed residential segregation, which increases exposure to health-deleterious factors in the environment while reducing access to health, promoting resources, and institutions.

And finally have the systemic-level thinking about these larger policies—societal level, sorry—immigration policies, Medicare policies, and even the labor system; so who's more likely to be employed in a job where they're able to, where you're able to work from home, where you're able to take time to sufficiently quarantine and heal without facing any repercussions from your job.

Inferring whether explicitly or implicitly that the cause of an observational disparity is due to some unchangeable biological factor, researchers tend to focus interventions and resources on these first two levels. So these lower levels include interventions related to health education, knowledge and capacity

building, which are necessary but not sufficient and completely ignore the interconnected myths of institutions and policies and practices.

What are the implications of essentialism and exclusion for science? Essentialism and excluding the social context can threaten the validity and reliability of risk prediction models. If the models are not specified correctly, results will be inaccurate and inconsistent. We see that in the case of race correction for kidney function, where we know the risk reduction is emphasized for Black Americans, and also researchers have found that the risk factors don't work for Black Europeans or patients in West Africa either.

Moreover, essentialism and excluding the social context allow for risk to be attributed to individual biology or behavior. This can lead to victim blaming, as we saw in the case of COVID-19. One article in *Health Affairs* suggested that racial differences were related to you, again biological susceptibility, where they say that there may be some unknown and unmeasured genetic or biological factors that increase severity of illness for African Americans. It should be noted that in the final published versions, the authors revised their content and said that these disparities were more likely to be attributed to societal factors, but this is a nice example of the predominant prevailing theory, which is that the severe illness that's seen in Black communities is the fault of the folks through some biological predisposition.

Additionally, Black communities were blamed for taking fewer COVID precautions. So not wearing masks without contextualizing it in terms of some folks that feared over-policing due to wearing masks in public locations. Also, these underlying health conditions that was one of the first risk factors that was discussed in terms of COVID, the increased disease in Black populations we've seen as a result of having poor health—but that was related to a variety of poor choices vs identifying, understanding, and describing these contextual factors that have really led to health disparities across a variety of factors.

While incorporating social determinants into risk prediction is needed, we understand it's not without its challenges. Some researchers are advocating for creating scores of social risks that can be incorporated into risk prediction models; however, there are many complexities with adding a polysocial risk score that we still don't know, including what variables should be added, how should they be measured, at what point across the life force do they matter for health.

Another challenge of including the social context for health in general is a lack of large cohorts that are sufficiently diverse to examine risk over time. So, for example, we know the hallmark Nurses' Health Study is responsible for a lot of what we know about women's health and lifestyle factors. But, as you can imagine, in the 1970s just after the passage of the 1964 Civil Rights Act, a lot of nurses were White and so is this cohort, it's still about 97% White.

The Black Women's Health Study and Jackson Heart Study are examples or predominantly Black cohorts that were developed to address the need for racial diversity, yet they are significantly smaller in size and investment. The smaller size matters when you begin to think about looking at the intersection of multiple social factors and multiple social identities. Additionally, while cohorts are helpful in improving our thinking of social determinants and which variables to include in risk prediction models, there is a need for data innovations related to COVID-19 right now that we've heard in Dr Krieger's presentation. Just aggregated data related to COVID infection, diagnosis, and treatment in breakthrough cases.

We have several calls to action. The first one is NIH and other governmental entities. For NIH, in particular, after an investment of \$3 billion and 15 years, the Human Genome Project is proof that with sufficient time and investment, we can tackle complex problems and make great scientific discoveries. We challenged NIH to make similar commitments to critically interrogate social determinants of health, you know, provide resources and support to collect the disaggregated data that's needed, also find more diverse cohorts that we need to help us incorporate social contextual factors in risk prediction models, and sufficient sample sizes that will be able to allow us to disentangle the intersection of race, class, geography, gender identity, sexual orientation, and other identities.

Some funds may come from increasing allowable funding for direct costs, for inflation at a bare minimum. What you see here on the left are funding rates to NIH in about 2003, and after adjusting for inflation—sorry about that—you see that we're now getting a lot less money. With more stringent requirements at NIH, in some ways, it seems like we're being asked to do a little bit more with a little bit less.

Also, for risk prediction models we're asking that you critically interrogate what you mean by race. So, do you really mean race or do you mean racism? And if it's meant to be a proxy for some other measure, use that measure instead. If it's not described, again, describe the hypothesized relationships and mechanisms, why would you expect this race and racism to impact health, so you don't leave it up to the reader, particularly given our history of assuming the biological consequences. As we learn more and establish evidence about contextual variables, it would be important to include these indicators and doing some additional research as well.

In the interest of time, I'll just summarize here from our paper. Essentialist terms and exclusion of social context leads to a tremendous distraction from root causes and, in a way, that allows folks that are responsible and able to really implement interventions to bring about change, to make them focus on individual-level factors that don't really address, again, these root causes and completely ignore the modifiable consequences of centuries of white supremacist ideology.

So I will stop there.

Graham Colditz: Thank you. And that sets up Rob Newell to bring a Canadian community-engaged perspective here.

Rob Newell: Thank you, I am just going to share my screen here. So when you can see that, you can hear me? Yes, oh full screen yeah perfect.

Thank you, everyone, and thank you very much for inviting me and for being here today. I'm sort of the odd duck on the panel because I'm the one Canadian, as mentioned. I'm coming to you from the city of Abbotsford; this is in British Columbia in Canada. It's in the territory of the Stó:lō nation. And from the University of Fraser Valley, which is the larger region.

The other thing that kind of makes me the odd duck here is that I actually don't work, or I don't do research in the health sciences field. I'm actually, my larger, broader research is, our umbrella would be

sustainability studies and, specifically, I look at each grade of planning for creating more resilient and sustainable communities.

Before getting into it, I figured that it makes sense just to discuss a little bit what I mean about integrated planning. In this context, it refers to using systems-thinking approaches to understand how, if you do certain strategies, policies and actions, how these link to a broader range of social, environmental, and economic factors. This sort of proof-of-concept or a conceptual model that you see right here shows how climate action and different climate action strategies, represented by the green nodes here, link to a whole variety of different social, environmental, and economic benefits and outcomes for community. so that's sort of an integrated planning perspective.

What got me invited to this presentation was this perspective paper that I wrote with a colleague, Ann Dale, who's at Royal Roads in Victoria, Canada. This is a part of a special series about cities and health where we reflected on early lessons in the COVID-19 pandemic and what it meant for sustainable community development.

Our papers specifically focused on this idea of, what's our vulnerabilities that COVID-19 highlighted from the pandemic for communities and societies at large? And we stress this idea that it highlighted these vulnerabilities; it didn't create vulnerabilities. It highlighted vulnerabilities that would also present challenges to other exogenous shocks, particularly climate change as we discussed in our paper. I'm not going to go through this full list in detail, but I'm just throwing some points out there. There was issues around supply chains, just-in-time inventory management, single-resource economies, and vulnerable populations, so forth. Things that are going to be challenges as we experience other exogenous shocks like climate change.

With this, we argued for integrated approaches to policy, actions, and planning so that we can increase resilience more broadly, more comprehensively to a variety of exogenous shocks. What you're seeing right here, this is not like a rigorous empirical research or diagram that is created from it, it was more a diagram that captured some of our examples and points that we put in our perspective piece. What it shows is on the left, you have these vulnerabilities highlighted by the COVID-19 pandemic; on the right you have vulnerabilities, issues, challenges that have commonly come up around climate change; and in the center, it shows that there are these planning and policy areas that can start getting you to thinking about how you can do integrated strategy. Just taking one of these examples, maybe looking at the second oval down in the green column, integrated health and sustainability, long-term planning, creating communities that have good greenways or infrastructure greenways. Also, equitable access to greenways and parks can do wonderful things for active transport. Trees are also good for— urban vegetation can do good things for controlling air pollution.

So this is good in terms of creating healthier communities, which puts less stress on health infrastructure. So that would be the vulnerability of the COVID-19 pandemic side, but at the same time, too, this green-infrastructure approaches are essential for climate adaptation, because it does wonderful things in terms of stormwater management, it reduces urban heat island effects, which is important as we experience more heat waves.

With this discussion of integrated planning and with respect to what we're talking about in this panel here today it's important to add this social justice and equitability lens on it. The first way that I want to do this is by presenting this term "climate justice." So when you're thinking about integrated planning,

it's important to recognize that climate change impacts do not affect everyone equally. There are some populations that are more vulnerable than others. What you're looking at here is a model, a diagram, that I had taken from Cassandra O'Lenick and her colleagues on where they're taking the Intergovernmental Panel on Climate Change's framework for vulnerability and applying it to issues around extreme temperature and air pollution. Air pollution being quite related to climate change through wildfires, as a lot of people in the West have experienced this year, and also in the fact that it's a co-harm that comes from sources of carbon dioxide. I will also often will spell out things like particulate matters. They look at the exposure to this health risk that could come from both the extreme heat and air-quality issues.

The vulnerability aspect basically breaks down vulnerability in two different components, saying that depending on populations' adaptive capacity where they have knowledge resources and community support to be able to challenge it, that affects how vulnerable they are. And also there are certain sensitivity factors that relate to demographics, like older populations will be vulnerable to some of these—more vulnerable to some of these impacts.

There's also this flip side of it where the solutions or the approaches to addressing some of these challenges don't actually benefit everyone equally. Just to take an example from a research project that we're doing right now— this research project's based on the idea that the original perspective paper that I've discussed at the beginning of this presentation here, where we're reflecting on COVID-19, doing a community-based research project in the Fraser Valley where Abbotsford, where my city is in, we're reflecting on COVID-19 in terms of what this has taught us about food systems vulnerabilities in the Fraser Valley, looking at through— as you can kind of see up here, this is a platform we use for online engagement. Looking at it in terms of food production, processing, distribution, food access, and government responses.

Some interesting tidbits have shown that the quote/unquote “solutions” or structures, processes, programs that we have in place to address some of these vulnerabilities don't actually benefit people right across the board equally. So in terms of food banks— the population of Abbotsford, or about 20%–25% of it, is South Asian either by immigrants or by ethnicity. Finding that some of our food banks don't really have culturally appropriate foods for the significant population in our community.

That might seem like a small example, but there's a lot of these examples that start building up, showing that, like our solutions and approaches for trying to increase resilience, aren't benefiting equally.

This leads to this idea of integrated planning requires participatory processes. In order to do this properly, and also research integrated planning requires participatory processes. If I'm doing research and creating tools approaches for integrative planning, it should be community based, involve the people that would use these tools.

Without derailing too much, I want to just read this quote here because I think it's very good for describing why integrated planning requires participatory processes. It says, “Governance is more effective if it occurs where the problem is felt (or where the opportunity actually appears), and in cooperation with those who are affected by it.”

You can read this quote in a couple ways. There's this sort of principle, the argument where people have a right to have a say in how their communities develop and places value develop, but then there's also

this practical argument. I've heard in the last couple of presentations discussion around lived experiences.

And if you're trying to do integrative planning where you're looking at the relationships between a whole variety of social, economic, and environmental outcomes, it really makes a lot of sense to involve people that have direct experience and knowledge in these different social, economic, environmental factors in the solutions and approaches for creating more sustainable, resilient, and healthy communities.

Specific tools that I want to talk about today is something that we're working with, is these reactive visualization platforms. The advancements in JS and video game technology has made this quite a possibility for creating these platforms that engage people in possible futures for the community and be able to have really in-depth conversations about why this might work, why this might not work.

I've actually just loaded up here, so you can take a look at one of the ones that we did in Squamish, BC. So, as you can see, what these platforms do is that it's a way of allowing people to walk through, in an area that we modeled, and turn on different scenarios that have different storylines. So as I click this scenario here, it just shows how can we can develop in the future. Right now, you can kind of see a lot of density, but there's a lot of different aspects to the scenarios.

So it gives people sort of a place-based approach of looking at this, and connecting with, and say there's things I like about it/things I don't like about it, these are the reasons why based on my experiences, my living within the community.

It's important to recognize that community-based research actually has a long history in health. There's a lot of work that was done in things like engaging communities around reasons why it might have obesity or nutritional issues in certain areas.

This is in the planning realm, but it has like a lot of relevance to the health world, too. It becomes a way of collecting information based on people's understanding, their lived experiences, the way they lived in communities, but it also could become a tool for sharing information. As you can see here for these scenarios, we also did a quantitative JS modeling exercise.

These maps are available to people that want to use them out there, and also some quantitative data. Just a visualization might not be all the information, people need to understand the implications of different scenarios and development trajectories. So you could put that in there and provide information.

Because it's a video game platform, sky's the limit. I mean you can kind of put also community feedback based on people's understanding of neighborhoods and saying, these are points and why you may want to or may not want to develop in a certain way. There are map-based views to it.

So it provides a number of different ways of being able to engage in information, ways of being able to invite people to share information about what they think communities should developed like, and also a way of being able to share and disseminate information to community members.

I'm not the only person that's doing this sort of thing. This is an example in Michigan, in Detroit. I think this is Chandler Cart but— it's Victoria Campbell-Arvai and Mark Lindquist worked on this platform using the same software that I was using, the video game software, to work with communities, local people

that lived in these neighborhoods and say like, “What sort of things would you like to see from green infrastructures as we build it here? What's the things that you're looking for?” and people express things like places to play, safe places to be, areas that would be able to help with stormwater management, but also green infrastructure that wouldn't be too costly, so we wouldn't have to carry that financial burden. So it becomes a platform to be able to engage people in sustainable resilient and healthy futures, as per what they will perceive, be able to provide that input.

This is my last slide here, and I'm going to wrap up. I think there's a lot of promise and work in this work and doing this, these community-based approaches to develop some of these planning tools and also to use them as engagement tools—it's by no means perfect. Participatory planning and community engagement is not a silver bullet for being able to address a lot of equity issues in planning, because often what can happen, and I've even seen this in my own research is that they could actually reproduce or reflect power structures. People that are showing up to the table and they're providing their voice—those community members, those stakeholders—could be people that have power within the community as well.

We're now putting in a proposal. We're actually going to put in next week to try and do a visualization process, creating visualizations with planning tools for food systems planning in a community, but using an equity framework to guide this. Now, this is an equity framework developed by Vanessa Andreotti, who created this, actually for critical literacy studies, to analyze an issue through like a, critique or an initiative through an equity lens. I'm working with some great folks that work in the areas of social justice and specifically food justice that are going to adapt this to a process of developing and engaging people through visualizations to see if this can give me another tool to bring in more diverse voices into the conversation and allow people to effectively use some of these visualization tools to be able to guide the planning of their home communities.

I should say to that I'm bringing the more folks in that have experienced food justice because that's not really my realm. So it might be, kind of seem like a bit a bit weird that I'm presenting this, but I just want to end off on this note that we're dealing with very complex issues so, my big recommendation, my reason for showing this slide is, it's really worthwhile to inform interdisciplinary collaborations that work with people that are outside of your maybe quote/unquote “comfort zone.”

Thank you very much.

Graham Colditz: Well, thank you for the heads up and the finish on framework. That's a theme across all the presentations here of the methods underpinning the science that may be aren't being used consistently, if at all, as the field has started to address this. We saw a notion that CDC and NIH have named priorities around structural racism, but how do we bring the science to the floor, to me becomes one of the cross-cutting issues that you're all addressing.

Does anyone on the panel want to take a first— answer that, and I'll ask others to use the chat or raise your hand if you would like to ask a question, please.

Nancy Krieger (she/hers): I mean when you say the science, I think that needs to be broken down a bit, because it means what's the theory, what are the methods, what are the hypotheses. All those need—what are the resources to implement that science? Who is engaged with that science? So there's many, many dimensions to what you're asking about.

But I think that if people have to start off with a clear conceptualization of understanding the relationships between structural racism and its many impacts on health inequities, and then, what that also means is, what are the metrics for measuring different aspects of structural racism over time in different societal contexts?

I could go on a great length about what many of these kinds of measures are that people are using in the US, beginning to remember that, for example, the history of Jim Crow lives in people's bodies still to this day, given what birth cohorts are exposed, and what that means in subsequent generations, what that means around the continued impacts of settler colonialism in the US context as well.

There are many parts that can be brought in the urban planning part, can bring in the histories of different aspects of legal, racial segregation that have occurred in this country, both prior to Jim Crow, historical redlining, also continued illegal discrimination.

It goes on through every institution. The whole point is that as a structural it's society-wide, and it's not just we'll look at it here only in housing, and look at it there only in regard to urban planning, and look at it here only in regard to, for example, healthcare institutions.

So there's a room for a lot of specific expertise and particularizing what measures are relevant to the concerns at issue, whether that's monitoring health, whether that is about explaining etiology and the reasons for what is being observed in the monitoring, or whether that's about developing and evaluating interventions. And also moving away from a standpoint that the interventions have to be first and foremost conceptualized by people that have primary expertise in health and are limited to health. Because that's not true—social change that affects health happens.

I'll stop there to give other people time, but I think that it's a question that is deeply theoretical, deeply practical, deeply methodological, and requires real resources.

I will just close by noting that I thought it was quite interesting that, when Dr Francis Collins announced that he was retiring and was being interviewed about some of his decisions, he was asked one question about COVID-19, about what he would have done differently with regard to, particularly, the rates of vaccination not being so great in parts of the US but also be the inequities in vaccination. And he just happened to comment that, perhaps, NIH should have invested more in social sciences.

Graham Colditz: Yes, thank you for pointing that out. There's a question for Rob. Are these visualization exercises directly linked to policy decision-makers?

Rob Newell: Yes, in a way, actually. I should probably say that one of my biggest research challenges, and the things that I'm really trying to do is close the gap between research and practice, and this is one of the reasons why I do community-based research. A lot of the work that I do, like the challenges itself,

are focused on community challenges. And then my actual research questions are really a matter of how can we do research in a way that it's actually has on the ground implementation. In the visualization of work that I did, and there is also the quantitative model—we created a model explorer that had direct linkages to community performance indicators that the community wanted to explore themselves. I'm trying to make it as relevant to their work as possible.

I still don't think that, I mean there is still a big challenge with being able to close that gap between research and policy. In the tools that are created you'll actually notice—they're publicly available—but notice that there's disclaimers on there. This is working with local government, saying that we want to be able to do stuff supports your goals but there's disclaimers and they're saying that this is a research project, it doesn't actually reflect an actual planning exercise. They wanted that in there to sort of cover themselves. There are definitely certain challenges in making that, in translating that research to practice. But you know, exploring roots and being able to get around it.

Part of it, I think, is being able to work with communities to train them in actually using these tools. I mean a lot of this stuff is open sourced, and I actually, you can target open-source and free programs, so that, like NGOs can pick it up, but that's going to be like, kind of the next step in my research. So people can use it, develop it, develop the visualizations, and take it on their own as their own tool.

I'll leave it there, because I see there's a lot of other questions, but I can certainly go on about this for longer.

Graham Colditz: Thank you.

Reactions from others on the panel to either of these comments?

Then, can I sort of ask, how do we move to really sustainable funding and action in these pieces? Nancy says, well, maybe we haven't funded behavioral sciences and admission, and we know the data shows who even gets funded on the behavioral science realm is very much not the underrepresented faculty. What are the questions that are being funded, and what perspectives are they bringing to the questions that might include these racism and related health effects?

Is that clear enough for Erika to take a stab at?

Erika Waters: I mean, I think, as I reflect on what I've seen both in the academic literature about who gets funded and what topics get funded and also other sorts of conversations and experiences, I think there needs to be kind of a two-pronged approach. First I really do think that there needs to be a greater education among grant reviewers about racism and structural racism and how it has such pervasive influences on health. In other words, to help reviewers understand that structural racism isn't just a niche topic for a few people to do research on but something that pervades the entire US society and influences everyone within it, regardless of their skin color. So I think there's that.

There's also greater funding for topics like this. As Dr Davis mentioned earlier, billions of dollars spent for the Human Genome Project and amazing progress was made. Let's take that to the problem of structural racism and other sorts of determinants of health.

Let's think about greater imagination, about what types of research studies are funded. Something that goes beyond, and I am guilty of this, too, but something that goes beyond kind of the kitchen-sink behavioral intervention approach. Something that that's a little bit more high-level thinking that allows to really target some of the core fundamental problems that people are experiencing. So there needs to be people's kind of structural change at the top and individual change for the bottom.

It is also important, just one last thing, we saw funding announcements come from NIH several months ago to address structural determinants of health, and that was great. The turnaround requirements for grants, however, to fulfill those, the due date for those applications was incredibly short. That preferentially benefits people who already have large funding, kind of enterprises going on, established researchers who are, due to the way it's worked for the last 60 years, who are primarily White and already have a lot of funding. So it's good that funding announcements are coming out there, but I think the structure of when those funding announcements are due and how they're evaluated and by whom they're evaluated needs to be considered a little bit more carefully.

Graham Colditz: Nancy, you want to add to that?

Nancy Krieger (she/hers): I also would just like to clarify. I don't think the issue is simply funding more behavioral science research unless the behaviors are specifically framed as being the behaviors of institutions. Because what matters for structural racism is also the question of what's actionable data, and actionable data is, in part, what is limited, what data can be litigated.

Because if you're talking about anything that's going to involve some permutation of, by different people's definitions, reparations but also government accountability for racial discrimination in the society and its continued impacts, as well as also the continued impacts of the settler-colonialism. You have to study the structural factors. And you have to study what the rules of the games are. This is about the behaviors of institutions like governments and also nongovernment actors, not just the behaviors of individuals.

And you also have to move away from frameworks that fundamentally stress quote/unquote "vulnerability," without any definition of who is making whom vulnerable, why, and how. Most vulnerability frameworks and measures have absolutely zero measures of any kinds of power relations. And again, if you want really to be taking into account how structural racism is harming help, you have to take into account power analysis, not just fiscal power, obviously—that ties to the questions about big cohorts and what you can investigate—but actual power and power relations.

And it also raises the question, which all too often is left out of most science, obviously, because it's seen as quote/unquote "controversial" is that if—"Why are things the way they are?" is also a question of why can't they be otherwise, and "Who?" and "What?" is blocking the way. In the case, for example, of climate, which was coming up here, and also COVID, let's look at the policies about who wanted to have what kind of workers exposed and what kinds of industries for their benefit and not for their health.

And that's really important question to ask about what went on when COVID policies, and also with regard to climate change, why is it so hard to have good policies? Who is benefiting from a fossil fuel-driven, consumptive, genetic economy? Those are questions that have to be part of what gets asked as scientists, because those are out there in the world driving the health patterns that we see.

I think that that's really important, and that again goes beyond notions of individualistic, behavioral responses. Health behaviors as such always occur in a context. People are never anonymistic little individuals regardless of social science and its legacy, as well, of methodological individualism that came on very strongly, Putin and the Cold War period, in particular.

So it's not that it's a question of biomedical vs social sciences, because both have their egregious sins of individualistic frameworks that deny responsibility of those who had power, creating conditions that are untenable and against the thriving of people who they're benefiting from not having power. So I think that those have to be part of the scientific agenda as well. That's not political ideology; that's reality as how population health happens.

Graham Colditz: Thanks and I might ask Kia, if you want to add any perspectives on this.

Kia Davis: Absolutely I agree, and just to highlight a point that Dr Waters mentioned. I think we in terms of how NIH structure review, traditionally it, as Dr Waters mentioned, it's easier for folks that are already have research labs and funding to pivot to new topics.

And so I would love to see an institutional practice from NIH and others to address that, so you're not having lots of people who have not been thinking about these issues for years doing disparities work in structural racism because now it's a hot topic, but really funding the folks that have been underfunded in the past who've been working on this for a while. So, in addition to who does the review and who gets funded, what institutional practices the NIH are putting in place so that folks that have been doing this work for a while and have been working with communities to do this work are getting the funding that they need to help advance science.

Graham Colditz: Shiriki's asked in a way, the sort of link between the way the communities perceiving these issues, where the science interfaces with these issues, and what policy does right.

Can NIH guidelines be rewritten, and I think we had that suggestion. Well let's actually create more of a mandate for inclusion and will let help move us faster than waiting for the natural process here. I think, Nancy, you wanted to answer that.

Nancy Krieger (she/hers): That was part of what I was addressing with the two-part mandate. I was suggesting for NIH.

And the point is that it's not just about including people, it's also how they are included, from what conceptual framework. You could include more people, but if you have an essentialist biological

framework, you're not going to do necessarily any better science; you're probably do more of the same, if not worse.

So it can't just be about that. It's not just about including the individuals as such, it's also managing that so that we might propose it. It's not just that you would include, for example, people from diverse groups that have social groups that have been racialized in various ways depending on, again, the particular circumstances of their society, but also, you have to include the metrics they get up, the racialized inequities that are always conjoined with economic inequities.

So it's about—and then that requires framework to do that—now, NMIHD does have a framework up on its website that makes it pretty clear that it's going to be, “Good luck!” if you're going to find any health outcome in the United States, for example, that's not going to show some kind of social inequities and outcomes. It's very hard to do.

And so, why is that the case? This is not a niche issue, again as we, as I said, and as others have said as well.

So it can't just be about including more people. One of the things that I think is very important for the first time, with the new NIH approach in its STRIDES program about dealing with racial, structural racism and health, is that it for the first time, it is distinguishing two separate points.

One is more inclusion of diverse people from different lived experiences in relation to primarily racialized groups, but not only. But the second is more of an emphasis on health, what they call health disparities research, health inequities. Because who you are does not necessarily dictate exactly how you think about things. You can have very conservative people, individualistic people of all different kinds of backgrounds and you can have people that are used to using more contextual, more social justice-oriented frameworks that also come from a variety of backgrounds. There's maybe a predisposition in one sense of lived experience, but I think we can also look, I'll spare some examples, that might be a little controversial here.

But I think we can look at examples of very prominent people who come from groups that have been considered to be racialized minorities have extremely conservative points of view and opposing them in other people. And the Supreme Court gives you some examples of that. And so I think that, it's really important to be clear on the distinction of not just inclusion and diversity, as if you're doing bean counting and adding more people, but also changing the actual recipe. Changing with the frameworks are, changing what the metrics are that have to be used around social group membership and the societal context, in addition to including more people.

Rob Newell: I'd love to build on that last point, especially like the bean counting aspect of things, too, and also tying in some of the discussion points around funding.

There was an earlier question from Karen about lack of trust in certain communities. Just presenting, giving you an example of what's going on in Canada. As probably a lot of people know, Canada's having a huge great reckoning with our colonial history. It says, particularly with residential school system and so forth. This has actually opened up a lot of funding for research around Indigenous communities, but you're starting to see some examples this is not implemented appropriately. There can be challenges.

Because in some cases, what actually happens is that you end up getting communities that are over-approached, over-researched in kind of inappropriate ways, because there's these funding pods that in some ways, actually commoditize in saying that you can actually get funding if you work with these communities.

Going back to Karen's point, thinking about a question, thinking about doing this appropriately. And then, what does it actually mean to do this work appropriately? We have some projects that involves a lot more relationship building. I'm not expecting to do this on like timelines that people are used to, which you submit the grant and start the project as soon as you get the funding that's not really the way it works. I mean that it's really more about relationship building.

Then also a second point. Being open to doing research and what's your, take your hands off the wheel and actually let the communities take control a bit more. It's difficult to write a grant that way because you're basically writing methodology saying that this is what we plan to do, but really what we plan to do is be totally responsive to what the community wants to see. There's ways around that, but be open to that that idea.

And then also her last point, too, is around the data ownership as well. I mean there are a lot of Indigenous communities that can be, that have been burned in the past by people going in and like kind of taking data and then just being more extractive than collaborative. It needs to put principles in ensuring that the tools of products that can come out it can be, have a lesser degree of ownership by the community. If that leaves you scratchy with my job as a researcher. Well, I mean I kind of view my job as a researcher as being able to improve these processes, to be able to allow for better community control, better data ownership, so that this stuff can actually improve people's lives. You almost have to kind of rejig your perspective of what you're doing as a researcher, just to be cognizant of the fact that sometimes just opening up costs of funding can actually lead to other issues. There needs to be kind of a way of doing it. I think I saw in the comments here, there needs to be a way of doing it appropriately.

Graham Colditz: And that might come back. I don't know if Karen wants to speak to her comment, but the, who's actually also writing the announcements, and, yes, they come through Counselor Councils, other Councils, of the individual centers within NIH.

Where is the expertise and how much is literally just trying to be responsive, even in the announcements, without the deeper understanding of all these issues? Erika?

Erika Waters: We're talking about the need for education among NIH staff. I also want to point out that this is beyond the corporate diversity and equity and NDI training. This is a fundamentally different series, to reflect Dr Krieger's work.

There are entire bodies of literature that go back decades that discuss the role of racism and the experiences of being a racialized identity on health and the lived experiences of people. I have to worry about the potential for kind of reducing all of that to an hour a week for 4 months of training.

So it has to be much more thoughtful and much deeper than I think, perhaps, most people are realizing. It's also important to understand that there's so many incredibly good scientists across different

disciplines, but not everyone has the training or exposure to the social sciences that would even bring some of these issues to the forefront. So I'm not going to pick on any particular discipline, but if I'm in a wet lab doing research, doing cultures, or if I'm working with animal models or something like that, my educational history has probably not led me to a course in anthropology, or health psychology, or community psychology, or behavioral medicine, or one of Dr Krieger's courses.

So there's a lot of work to do.

Graham Colditz: Super. Karen, do you want to comment?

Karen Emmons: Yeah, I was just thinking in terms of like, what are the levels that we need action at? Just kind of going back up to the NIH level.

I was sitting, at the time that all of the COVID vaccine trials were being launched, I was invited to be part of a town hall that was a giant number of people. Francis Collins was there. He introduced the town hall; it was on community-engaged research.

Two things really struck me on that. One was that Dr Collins came on and said, "We're so glad to have you all here. The trials start next week, and we know we have to be more community engaged, so we're here today to learn from you how to do community engagement."

And I thought, oh boy, that's about 6 years too late, number one, and number two, the entire set of speakers talking about the issues for this community, and that community, the other community all had "Dr" in front of their name and mostly were not people representing those communities. I really feel like somehow we have to start to target, work with, our highest levels of NIH leadership to help them understand more about this. I think it's become a little bit of a buzzword, and just something we can tack on, and we got to say it, and it's all the right words, but it's so much deeper than that. If we don't start to integrate that from the very top and flow it down, I think we're not going to get very far.

wvega@fiu.edu: Yes, I'd just like to make a point. I think, at least at the level of the United States, because these are sort of international issues ultimately, but I think at the level of the United States, you know, we face the enormous basic contradiction that the kind of research the NIH is funding is not the kind of research that gets down to the local level, with changes really going to be made in the power structures and jurisdictions that are always combating, adversely quite often, come up with solutions and look for resources.

Making the sort of transition into understanding that really, we have to get much closer to the decision-making process and formulate our information in ways that are useful to that decision-making process and develop influence. And we haven't done that very successfully, and the NIH is really not very interested in that, and so we face a fundamental contradiction, seems to me, in our capacity to really influence this process. We need to figure out what to do about that.

Graham Colditz: Thank you so maybe I can ask Kia and Erika if you're actually encountering more resistance in cooperation in your efforts to foster decentralization of race, and do you have concrete examples of the types of errors that can be made?

Erika Waters: Kia might have a different perspective on this. I have not heard anyone who is really pushing back against these ideas. Reception is generally positive, but puzzled, where people become stymied; it's the sheer complexity. I think that's the major, the major stumbling block is there's general agreement that once people are made aware of the issue, there's general agreement that there's a problem. But the solution, the magnitude, the complexity of the solution is kind of daunting to people.

Kia, has that been your experience as well with folks you talked with?

Kia Davis: This has mostly been my experience. I have seen a little bit of you know, but there are some biological components, aren't there? So, again, kind of ignoring some of the multilevel influences, think about the biological piece, but instead of actually accurately capturing it in terms of genetic ancestry some of the embodiment that we know occurs; it's just framed very differently.

I would agree there's the there's a lot of befuddlement about how to do this and how to do this correctly. If we want to talk about racial differences, because that's the only variable that we have, how do we do that correctly so we don't offend? We're really incorporating and thinking about the correct variables that lead to these disparate health outcomes that we see. So far it has been positive, and there has been just a lot of, I guess, requests for advice on how to do this work well.

Graham Colditz: The biomedical model is so dominant in the thinking. I was preparing a presentation for the Board of Scientific Advisors and using obesity as a major burden driving cancer, and someone wanted me to take out the social, ecological model. Well, it was too complicated to present to the Board of Scientific Advisors. And that's been in our literature for so long. "Take that slide out!" I had to take that out. So there's major tension at that level around many of these issues, clearly.

Erika Waters: I do wonder how much of this, and I'm going to be very straightforward and blunt here, I do wonder how much of this is just that White people haven't been comfortable talking about the race, and we need to become comfortable talking about race and interrogating our own beliefs and the implications of those beliefs, and perhaps even past actions, on folks from marginalized and racialized populations.

Kia Davis: I've also heard enough folks that want to do community-engaged work now. How do they approach it, because when they go to communities, the communities want to know why they're there, and my advice is you should have an answer to that question. You should know why you're there before you decide to partner and engage with the community. I agree that a lot of it is, or maybe some of it, is just being uncomfortable with navigating this new space.

Graham Colditz: Nancy, you want to add to that.

Nancy Krieger (she/hers): I would just like to extend on that. I think it's not only talking about quote/unquote "race," it's talking about structural racism, it's talking about the histories of societies. I think that there's a framework that's been developed and extended now from New Zealand that's extremely important that was developed by MariHealth on professional, specifically nurses, on cultural safety as opposed to cultural competence. One of the major distinctions is that cultural competence, this is in terms of engaging people to actually think about who they are in their own societal context, cultural competence has usually been framed as, what do quote/unquote "we" usually not well-identified need to know about quote/unquote "them," usually the racialized groups or some other group that has been at the short end of the stick of some version of oppression or exploitation. And instead, cultural safety starts with the premise that the person who's doing the work as a health professional, as a health researcher, has to start, first and foremost, by looking at their own position in society, what power relations they are nested in, what that means in terms of their relationship, whether directly to patients that they take care of, or to potentially people that are participants in their studies, let alone their coworkers.

It's an acknowledgement of dealing with these things is the social categories, that they are born out of histories of unjust power relations. And maybe that's not comfortable to talk about, but that's also the reality that we live in.

And I think that breaking it down and teaching the history, I'm an educator among many other things, and I'm an educator because I believe everyone can learn. Yes, people come in with different, of their own lived experiences and that informs what people learn, and how they learn, and what they can bring to the different learning contexts. But I've also believed people can learn. I'm just about finishing up teaching my Fall one class on you know the that teaches people about different theories of disease distribution to understand health inequities in context, deals with history, deals with society, deals with injustice. Watching students develop over the course of 8 weeks and get information across multiple disciplines, because this is, of course, what's required for all the people in the Population Health Science PhD program in our school, which cuts cross five departments.

There are students that come from environmental engineering backgrounds who have never had any exposure to any of this, and they are finding out ways that they can start to apply this to the kinds of science that they do. And so, for me, that's a cause for optimism. So yes, there can be quote/unquote "discomfort," I get it, but also there's a need to be actually having the relevant scientific expertise and pitching this work in relation to two fundamental principles matters.

One, if you don't take these ideas seriously, you're going to do harm to people.

And we have a commitment not to harm people, we have a commitment not to harm communities, we have a commitment, actually to try to protect people's health and to promote health equity. And the second is, if you don't pay attention to these kinds of things, well for a scientist, that means you're actually out of date. And that usually is another way to get people's attention.

There's enormous literature out there that supports what we're saying; it's not a matter of individual conviction or ideology.

Graham Colditz: and Rob, you mentioned that Canada's right in the mix of dealing with this from the schooling travesties. Is there hope that the country will respond faster and more nimbly than the examples we have here in the US?

Rob Newell: Yeah. I mean, I'd like to put a note of caution in that because I think there's something to be said, too, as we're trying to reckon with you know our really dark, terrible history and also trying to work towards reconciliation. This idea of saying, okay, so now we're doing work in which you know to, just put it bluntly, like the White population is a seller population is trying to reconcile with Indigenous population. That's means we're doing work around, trying to create more diverse, harmonious community.

But then it sort of homogenizes? Like, the different racial issues? I just returned from like a perspective in Abbotsford. We talked about a lot of food planning, food strategies, and ways that include like Indigenous food sovereignty. That has become on the radar and so forth. But then, this is anecdotal, this is not like actual research data but some of the local food strategies that we showed had been implemented around marketing and showing local food opportunities, were just fully ignored, like the South Asian population that has a huge participation in the agricultural sector around here. It's about 20% to 25% of the population in Abbotsford itself. Like a group that just did not feel reflected in some of these efforts. Then I'm saying like, okay we're kind of reckoning and we're doing this work towards the Indigenous folks. I think it's, like it's worthwhile to try not to homogenize the issues among all the groups. And understand that it doesn't mean we are making progress in all sectors. It seems that there are some areas that have different challenges, new challenges. There's also issues in homogenizing challenges among the Indigenous groups, because not all Indigenous cultures are the same, they have different challenges across Canada. I think that's one of the things that we need to think about, too. Let's not try and put this all under one umbrella, and understand that it is complex, and the challenges are different, and we do actually need to address these things culture by culture and group by group. Yeah, because I've seen concerns about that almost blanket, umbrella approach that's been done.

Thank you.

wvega@fiu.edu: Yes, I think we're dealing with some different levels of depth in each of these fields. That's why it's so incredibly complex. I mean, if you want to go to some of the deepest caves, just look at genetics. I've been working in Alzheimer's disease now and, I remember about 5 years ago speaking to a geneticist about including that, and genetic racial variation was ridiculous to them. You don't need it, you can do better work by keeping a much more narrow focus. And they were absolutely obstinate.

And now it's completely turned around, of course. It was forced by NIH changes and policies. But definitely now, you can see the change in the perspective, but it's a very slow evolutionary process, clearly. And then even then, when they start getting genetic information on different groups, what will

they do with it? Are they going to look to understand the social-biologic interactions and processes or not?

I remember, again about 5 years ago, they were talking about 70% of late-onset Alzheimer's was just simply due to genes. Now it's down to 7% because the interactions in different ethnic groups are so different. It's a so-called high risk, it's not necessarily stable across different ethnic and racial groupings.

Now we find a great difference in questions of interpretation of what do these sort of fundamental findings really mean and in the long haul? I think this is a long evolutionary road that we're on and, as I say, some caves are much deeper and much more difficult to change, and we really have to influence those continuously in policy. The NIH, it seems to me to keep demanding that they keep looking at these, what I would call pathological processes and health-promoting processes that exist between environment and actual substrate of things like biology and genetics.

Graham Colditz: Thank you. If I'm reading the schedule correctly, it's my turn to wrap up, thank the panel for the time you took to prepare your remarks and for contributing helpful discussion here.

I'll turn it over to Karen Emmons.

Karen Emmons: Thanks so much, Graham, and again, thanks to our panelists. That was really spectacular. I want to just take a moment to give you a round of applause, virtual or otherwise. And Graham, thank you for a wonderful job moderating That was really terrific.

I believe this is taped and will be available through some magic means, so if you're interested in it and don't have access to it, just drop me an email and I'll make sure you get access to it.

So, I would like to thank very much the members of the public who joined us today. We are now going to transition into a closed session for members only, and so we'll bid you adieu and wish you the very best for your weekend.