Episode: Ethics Talk Videocast Transcript – Hacking Structural Racism in Health Care

Guests: Emre Ergecen, and Freddy Nguyen, MD, PhD, and Sai Rajagopalan, PhD Host: Tim Hoff and Audiey Kao Transcript by: Cheryl Green

Access the video and podcast here.

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TIM HOFF (Host): Welcome to another special edition of *Ethics Talk*, the *American Medical Association Journal of Ethics* podcast on ethics and health and healthcare. I'm your host, Tim Hoff.

This episode is an audio version of a video interview conducted by the journal's Editor in Chief, Dr. Audiey Kao, with Emre Ergecen, a 5th year PhD candidate in the Department of Electrical Engineering and Computer Science at Massachusetts Institute of Technology, Dr. Freddy Nguyen, a 2nd year pathology resident at Mt. Sinai Hospital in New York City and a post-doctoral fellow at Massachusetts Institute of Technology, and Dr. Sai Rajagopalan, a 4th year medical student at Vanderbilt University School of Medicine. They joined us to discuss design thinking as a way to find solutions to combat structural racism and advance health equity.

To watch the full video interview, head to our site, <u>JournalofEthics.org</u> or visit our <u>YouTube channel</u>.

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AUDIEY KAO: Welcome, all of you, to Ethics Talk today.

SAI RAJAGOPALAN: Thank you, Audiey.

FREDDY NGUYEN: Thanks.

EMRE ERGECEN: Thanks, Audiey.

KAO: So, the COVID-19 pandemic has dramatically exposed racial inequities in health and health care. As the individuals who launched MIT Hacking Racism in Healthcare, you all wanted to create a space for collaboration to dismantle racial injustice in healthcare delivery and address the social determinants of health. Yet when one thinks about hacking computer viruses and someone engaging in high tech, misbehaviors come to mind. So, how can a hackathon help when racism is not a computer virus that can simply be eradicated through a technology fix?

NGUYEN: So, hackathons is personally part of the DNA at MIT. There's usually tons of groups around campus that do hackathons, and it's definitely not in the traditional sense of hacking into a computer system or breaking into things. It's really about a creative use of ingenuity. And so, our hackathons, especially the ones that have been pioneered by MIT Hacking Medicine, and been optimized over the last 10 years, really focuses on bringing a diverse set of people together to problem solve around these issues. And so,

especially in healthcare, when you think about it, it's a very complex system where oftentimes, a person who is prescribing the solution versus paying for the solution versus experiencing the solution, oftentimes, three different entities altogether. And that's in the simplest form. And so, for us, as part of these hackathons, it's about bringing all of those stakeholders together: whether it's the clinicians, the scientists, the engineers, the coders, the programmers, the user designers, the patients, the business folks, the user designers, and insurance and payers and so on. So, basically, think about every major stakeholder, and we want them all at the table.

And the reason for that is that some of the things that we've noticed, especially if you think about how typical research, and especially biomedical research, often happens in the silos of research labs. And it usually takes a bit of time before they start engaging with the other stakeholders to kind of balance their solution and the ideas they have. And by the time they do that, they realize that they haven't taken into account certain principles or certain restraints or constraints in terms of how the solution might be implemented into account. And so, then, yes, they've taken two steps forward, but they're taking one step backwards to now try and incorporate that new feedback. And so, by having all those stakeholders at the table from the very beginning, and not even before the solution development, but at the problem definition aspect, the quicker we can accelerate that whole process.

And so, we've done this quite a number of times with our healthcare hackathons when the issues around systemic racism started to really bubble up to the top during the summer, we wanted to see, could we pivot the same type of mentality and methodology towards this complex problem as well?

KAO: So, can you elaborate a little bit more about how the hackathon—and my understanding is that you all took it, you all took the approach of design thinking—so, how does design thinking help all of us tackle big problems such as structural racism?

RAJAGOPALAN: Yeah, I can talk about that, Audiey. Thank you for the question. Yes, all of the hackathons that we've held so far as part of the COVID-19 Challenge, also the Hacking Racism Challenge is centered around design thinking. And as Freddy mentioned, this is not the typical process of research that everyone's used to in academia. The goal here is to deeply understand the problem. And the first step in design thinking is to empathize with those who are actually facing the problem in daily life.

KAO: Hmm.

RAJAGOPALAN: And so, the teams have to—essentially anyone who's trying to use design thinking to solve a problem has to—first really get into the world view of those who are facing these issues day in and day out and empathize with them and then understand what they're going through before they can actually even comprehend how or what needs to be done about it. So, that's always the first step in design thinking, and that takes the longest period of time to get it right. The next step is to actually define it in a way where it can be, one can find a solution to the problem. So, even though you understand the daily reality of what's going on, you have to somehow convert it into an

analytical problem that needs to be solved. And so, that's the definition part. And only then do people go into teams as interdisciplinary teams with a wide variety of backgrounds to ideate on that problem.

So, you empathize, you define, and then you can ideate on the problem, which means, okay, here's the problem that we've defined. What are the different ways, or what are the different solutions that are possible? So, start without any constraints, and then start adding constraints to it. And then once you come up with a solution that you think you can implement quickly—which was a goal for us because we didn't want to go into a five-year research project of sorts—adding all those constraints, and then you can prototype. And the whole idea behind design thinking is you create fast prototypes, then you give it into the hands of the users, and they will give you feedback on how the thing works. So, in this case, this is a very unique sort of environment when we want to talk about structural racism and applying design thinking to that.

And the final step, which we are embarking now on, is the testing phase where people implement their solutions or their ideas in the real world and see what happens and then pivot based on what the real need is and what the constraints are and how they need to make leaps and bounds forward.

KAO: Yeah. If I can just follow up on what you just said. Can you talk a little bit more about how you get the groups to develop that quote-unquote "empathy?" Because you said that that was the part that takes the longest.

RAJAGOPALAN: Yes, I can definitely talk about that. So, in many ways, this hackathon, the Hacking Structural Racism Hackathon, was different for us because obviously, as you see, we are all men. And we did not feel like we had the right backgrounds to talk about these issues because none of us faced a lot of these in our daily lives. So, the first step for us was to introduce the teams who came from all over the world to what the problem was. And we held a listening session during the week of September 25th, that weekend, where we had experts who tackle these problems daily in their daily lives, whether in terms of healthcare, whether in terms of socioeconomic problems, whether in terms of other education, and so on, come and give us a listening session. So, essentially, we just listened to what they had to say on that topic as experts. And that formed sort of the bedrock, what participants heard from them.

KAO: Right.

RAJAGOPALAN: And these are people who tackle these in their daily work and also lives. So, that's the part where we try to provide some input for the empathy part of this. And we also tried to create a document, a living document, with resources and journal articles and press articles that talked about a lot of these issues that happen in our society. So, that was our way to facilitate that part. And also the third part was because we wanted interdisciplinary teams and we recruited widely from all demographics, all backgrounds, all professional, socioeconomic backgrounds, the teams themselves had people who face these sort of things in their daily lives. And that was the third step to providing empathy.

KAO: Yeah. So, I think to just jump off on what you just said, much has been written about how the C-suites in sectors including healthcare and Silicon Valley are dominated by men, specifically white men. And so, why was it important for all of you to create a space where the participants were from diverse backgrounds?

RAJAGOPALAN: Yeah, so as I briefly mentioned in my previous comment, without having a diverse background, we do not arrive at a solution that works in the real world. Because if we have a room full of people that think just like us, we have our own biases that we come into the world with: the way we grow up, the way we live our lives every day, and biases that we just don't know about. So, that's why it was important for us to make sure that the teams that formed were diverse in terms of not only demographics, but also life experience, educational experience. We did not restrict anyone based on whether they had a degree. We were looking for pretty much everybody, as Freddy said, who was passionate about solving this problem of structural racism in healthcare.

And as you discussed, a lot of the leadership, not only in healthcare, but also other industries is dominated today in this country by one particular group, and that's why we feel there are a lot of these problems. Because even if the people themselves don't have any ill intentions towards anybody, they're prone to their own biases.

KAO: Sure.

RAJAGOPALAN: So, they're blind to a lot of the problems in the world. And that's why it was important for us to do that.

KAO: Yeah. So, I imagine there were quite a few unexpected ethical challenges that you will have to overcome in the run up to and during the actual Hacking Racism event. Can you share with our audience some of those challenges?

ERGECEN: Sure, Audiey, maybe I can answer that question. And it's a really nice question. When we started this Hacking Racism initiative, we were really excited because we knew that it was a really big problem. But as you can tell, we're just, we're all like, Freddy, Sai, and I are coming from different backgrounds, but we knew just a little about this racism issue in healthcare. At first, we wanted to tackle a broader perspective of this problem. But one of the things that we thought about is that this racism is so prevalent that we won't be able to address it in whole. And we just decided to focus into healthcare because that's our expertise.

And the second thing is that without involving the rights stakeholders, any hackathon that we organize is meaningless. And we organized five or six hackathons prior to Hacking Racism. And the way we looked at it was we have a really nice toolkit, but as we actually talked to other people and other stakeholders, we understood that we actually knew a little about the problem. So, at that point, we took a different stance, and then we said, okay, maybe we should engage a diverser set of stakeholders. And in the meantime, we involved, Black Tech Matters, a fully Black initiative, trying to reach out to HBCUs trying to empower those people. And at the same time, we used MIT resources as well. And one of our organizing members is a Martin Luther King Fellow at MIT, Charles Senteio. And he gave us a lot of insights as to how we can tackle these problems during the hackathon. So, it was a great experience. And our approach was that we had this hackathon toolkit, and we wanted to make sure that we involved the right stakeholders so that this toolkit actually serves a good purpose.

KAO: Sure. So, finally, as we near the end of our conversation today, how well do you think the Hacking Racism event or initiative, how well did it meet its intended goal? And what do you see as the future of hacking racism to advance health equity?

ERGECEN: I think it's really important question. I think the initial goal was, to our naive perspective, was to educate ourselves and our participants. We just started with ourselves, and we wanted to disseminate the information, and that's why we organized this listening summit. We want to, in this listening summit, one of the days—I think it's a two-day listening summit—and the final day was about identifying problems which can be solved in a hackathon, in the course of a hackathon. That was really useful for our participants and for us as well. It's made us define the problem statement more clearly. But at the same time, when you come to the hackathon, I think it was a really good platform to, I don't know, bring people together, make them listen to each other, and just discuss these problems and just try to empower them to find some solutions to these problems.

So, I think bare minimum is to provide this platform for listening and entertaining ideas for solutions. But at the same time, if teams want to take their solutions further and if they would like to implement their solutions, they're offering them our partner support, which we call the post-hack. So, if they want to do this and if they're really driven and engaged in their ideas, we provide them mentoring support, we provide them incubator support as well. So, we want our teams to make an impact, and we are trying our best to push them forward.

KAO: Sai or Freddy, do you have any thoughts about lessons learned in this recent event and what you would do differently if you were to continue on with this going forward?

NGUYEN: I think just like other problems, I mean, this is a very, very complex issue, as one can imagine. And so, I can't stress enough the importance of having all of those stakeholders engaged and involved at every step of the way, whether that was on the organizing team itself, whether that was as part of the listening summit that we had prior to the hackathon itself, whether it was participants, mentors, judges, partners are involved. And I think that's still something that we're constantly looking to expand and continue to do so. And I think that's probably one thing that we could always use more of, is to have the diverse stakeholder group as part of each of those components. And that's important not just for the event itself, but really to build that community and that ecosystem of individuals and of partners and entities that can really come together to tackle these tough challenges.

RAJAGOPALAN: Yeah, and on my end, I think one of the things that I definitely learned was, as Emre said, we were oblivious to a lot of these issues ourselves. So, that was the first thing: empathizing was the biggest goal for us through this initial hackathon. I think we at least achieved part of that goal for us. Now, in the post-hack phase, we're hoping to have many more participants from the health systems and medical schools.

And I think, as you initially pointed out, the word "hackathon" doesn't really connect with that audience because they don't understand the concept of design thinking, because it's not a part of medical school curriculum anywhere.

KAO: Right.

RAJAGOPALAN: And I at least feel that it definitely needs to be. The only school I can think of that has that as part of the curriculum at Vanderbilt. And I'm not saying that just because I go there. I don't know many others that do that. So, that is another challenge. We hope to educate the public about design thinking and how they can be involved in solving big problems and not just stay out of a big problem, thinking that they can't do anything about it. So, everybody can do something. And taking that small step, whatever small step that is, is what these sort of hackathons that emphasis on design thinking bring people together for.

KAO: Yeah. Well, on that aspirational note, I want to thank Emre, Sai, and Freddy for sharing their expertise and insights with our audience. Thank you all again for being guests on *Ethics Talk* today.

RAJAGOPALAN: Thanks, Audiey.

NGUYEN: Thanks for having us.

ERGECEN: Thanks, Audiey.

KAO: For more <u>COVID Ethics Resources</u>, please visit the *AMA Journal of Ethics* at <u>JournalofEthics.org</u>. And finally, to our viewing audience out there, be safe and be well. We'll see you next time on *Ethics Talk*. [bright theme music returns, then fades]