Episode: *Author Interview: "How Old Are You, Actuarily?"*

Guest: Diya Uberoi, PhD, JD, LLM, MPhil
Host: Tim Hoff
Transcript: Cheryl Green

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[bright theme music]

[00:00:03] TIM HOFF: Welcome to another episode of the Author Interview series from the *American Medical Association Journal of Ethics*. I'm your host, Tim Hoff. This series provides an alternative way to access the interesting and important work being done by Journal contributors each month. Joining me on this episode is Dr Diya Uberoi, the associate director of the Genetic Discrimination Observatory and the senior policy analyst at the Centre of Genomics and Policy for the Global Alliance for Genomics and Health. She's here to discuss her article, coauthored with Abby Rud, "*How Old Are You, Actuarily?*," in the December 2020 issue of the Journal, *Aging Is Bad for You?* Dr Uberoi, thank you so much for being here.

DR DIYA UBEROI: Thank you so much for this opportunity. It's great to be here. [music fades]

[00:00:49] HOFF: So, what is the main ethics point that you're making in this article?

UBEROI: So really, I think at the crux of this article, really, is this concern around this conflation of scientific objectivity with fairness and justice. And what is important to realize is that genomics, and science in that sense, is never truly, I think, neutral or unbiased. Let's look at just even genomic data sets, which we know can be heavily skewed towards European ancestry and that, as a result, can at times create inequities in research outcomes. And so, while I think similarly certain population groups or equity-deserving groups may statistically show even age acceleration on average, which might be faster, but when you apply that kind of data now in other settings, such as in insurance or in private sector contexts, it can really perpetuate discrimination and lead to further inequities in outcomes on the ground.

[00:02:00] HOFF: And what should health professions students and trainees in particular be taking from this piece?

UBEROI: I think, really, what wants to come out right at the forefront for that is really that as health care providers in and of itself, and when we think about the health of our patients, we can't always look towards medical outcomes. Our health today is really defined also by the broader context in which we live. And so, we have to also think about the social aspects of this, and we have to go beyond just clinical settings. And so, this way when we think about genomic technologies and emerging technology in this way where governance frameworks are still also evolving, I think health care providers also have to understand how the health that is then, the data that is generated about

patients, how that could be used, and how that can also have an impact on them. So, just as you, I think, can sometimes weigh the out-of-pocket costs of, say, medication, and we look into that against the benefits that medications might have, you similarly have to also think about, I think, the social impacts of genomic interventions and how that can also have an impact. So it's really going to be important as we go forward for health professionals, students, etc., to really be informed about different protections that might be afforded in countries and the broader implications of genomic technologies.

[00:03:42] HOFF: And finally, if you could add a point to your article that you didn't have the time or space to fully explore, what would that be?

UBEROI: The real global impact of something like genetic discrimination today. And that's because I think we were really focused on Canada in and of itself in our article. But the idea is that we have different countries around the world, and while some are still developing different legislation to deal with genetic data and its use, but if we want to think about the global sphere and the influence as a nation going forward, I think it's also going to be important to start considering how we want to lead and what that means for different frameworks, and how we need equitable, robust frameworks that can actually really serve as a positive model trying to address these issues right from the ground up itself. [theme music returns]

[00:04:46] HOFF: Dr Uberoi, thank you so much for your time on the podcast today, and thanks to you and your coauthor for your contribution to the Journal this month.

UBEROI: Well, thank you so much. I appreciate this.

HOFF: To read the full article, as well as the rest of this month's issue for free, visit our site, journalofethics.org.