

Episode: *Author Interview: “How Should Epidemiologists Respond to Data Genocide?”*

Guest: Abigail Echo-Hawk, MA

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 Abigail Echo-Hawk, a citizen of the Pawnee Nation of Oklahoma, the executive vice president of the Seattle Indian Health Board, and the director of the Urban Indian Health Institute. She's here to discuss her article, coauthored with Dr Sofia Locklear, Sarah McNally, Lannesse Baker, and Sacena Gurule, “*How Should Epidemiologists Respond to Data Genocide?*,” in the January 2025 issue of the Journal, [Epidemiology and Clinical Practice](#). Abigail, thank you so much for being on the podcast.

ABIGAIL ECHO-HAWK: Thank you so much for having me. [music fades]

[00:00:55] HOFF: So, what is the main ethics point that you and your coauthors are making in this article?

ECHO-HAWK: That we need to focus more on indigenous data sovereignty and understanding of how tribal nations have the ability to govern and be part of their data and what data genocide looks like in that. The point of the article is really focused on that American Indian and Alaska Native people, along with other indigenous people, are purposefully eliminated in data sets, and that purposefulness is grounded in institutional racism. So, many epidemiologists have no idea they're actually participating in it. So we hope that this article brings about awareness and opportunities for epidemiology to look at their practices that may be grounded in structural and institutional racism, identify the opportunities for meaningful change, and partner with communities. There's also opportunities to look at how these concepts could be applied to other populations.

[00:01:53] HOFF: And so, what do you see as the most important thing for health professions students and trainees to be taking from this article.

ECHO-HAWK: That data genocide is real, that the purposeful elimination of indigenous people in data sets is resulting in the deaths in my community. During COVID-19, I lost more than ten family members myself. I operate a Indian Health Service clinic in Seattle, Washington where I saw not only Native people dying there, but across the nation. My organization published a report during that time that showed that when the data hadn't been gathered across the United States, the US government did not allocate resources to stop COVID-19, and as a result of that, more American Indians

and Alaska Natives died. And in fact, we lost more than seven years of life expectancy across two years during the COVID-19 pandemic.

This data genocide is exactly that. It is causing the deaths of American Indians and Alaska Natives, as we have a treaty right to resource allocations based on data. And the field of epidemiology has the opportunity to make incredible, meaningful change that can be a part of halting this genocide, addressing the health inequities that currently exist, and truly seeing what health equity could look like when epidemiology steps up and says we can do things differently.

[00:03:20] HOFF: And finally, if you could add a point to your article that you didn't have the time or the space to fully explore, what would that be?

ECHO-HAWK: I would add the stories of the communities that I'm speaking of: the mothers that lost their children as a result of the missing and murdered indigenous women's crisis that is not properly being documented within data right now. I would share the stories of the family members who lost loved ones to COVID-19 that was, if given the appropriate resources, could have possibly been preventable. I would've shared the stories of the communities. And that's the one thing as epidemiologists we have to remember: that each statistic is a family, is a community, is a tribe, is loved ones that matter. [theme music returns] And we have to remember that the data, the data is stories.

[00:04:09] HOFF: Abigail Echo-Hawk, thank you so much for your time on the podcast today, and thanks to you and your coauthors for your contribution to the Journal this month.

ECHO-HAWK: Thank you so much, Tim.

HOFF: To read the full article, as well as the rest of this month's issue for free, visit our site, journalofethics.org. We'll be back soon with more *Ethics Talk* from the *American Medical Association Journal of Ethics*.