Episode: *Ethics Talk: Why Has US Health Research Shifted From Social and Environmental Factors to Genetics?*

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[mellow theme music]

[00:00:06] HOFF: Welcome to *Ethics Talk*, the *American Medical Association Journal of Ethics* podcast on ethics in health and health care. I'm your host, Tim Hoff. The promise of genetic research is compelling. By decoding a patient's genome, we could provide personalized risk assessments and treatments into previously undiagnosed diseases and other "medical mysteries" to say nothing of the profit incentive for companies who develop new genetic tests or pharmacogenomics therapies.

Over the course of the mid-to-late 20th century, advances in DNA sequencing technologies and milestones, like the completion of the Human Genome Project in 2003, led to an increase in funding, both federal and private, and an increase in the attention of health researchers toward the promises of genetic medicine.

Evolving parallel with genetic medicine is our understanding of environmental and social determinants of health. Air pollution, access to healthy foods, and insurance status, for example, are well documented influences on health. In fact, studies suggest that clinical care only accounts for around 15 percent of a person's health status. Put another way, social and environmental determinants of health could be responsible for around 85 percent of a person's health. Despite the strong and growing evidence of their importance, funding, especially public funding, for research into environmental and social determinants of health suffers from a lack of a clear path toward profitability.

DR JAMES TABERY: Combating structural racism is not the kind of thing that companies are inclined to invest in, because it's not clear that they would know how to make money off of doing that.

HOFF: The trend in US scientific research that prioritizes genetic understandings of health and illness over social and environmental sources of illness is not a value-neutral happenstance of history. As a reflection of our scientific and medical priorities, it deserves our attention and scrutiny. So, joining me on this episode to discuss the competing visions of what constitute "legitimate aims of scientific study" and how US research priorities have shifted through the late-20th century to present, is Dr Jim Tabery, a professor in the Department of Philosophy and a member of the Center for Health Ethics, Arts, and Humanities at the University of Utah. Dr Tabery, thank you so much for being here.

TABERY: Hey, Tim, thanks for having me. [music fades]

[00:02:34] HOFF: In your book, *Tyranny of the Gene*, you contrast Rachel Carson's work on environmental harms of the insecticide DDT with contemporary emerging research into what was then called "genetically conditioned drug responses." These competing visions of what constitute legitimate aims of scientific study are then traced to the present. Can you start with an overview of how the US scientific community has shifted focus away from social and environmental determinants of health in the pursuit of gene-based and what has been called personalized medicine?

TABERY: Yeah. You bet. Great question to kick it off, because I do think that's sort of the inherent tension that we want to focus on. There are really sort of two evolutions that are happening side by side throughout the mid-to-late 20th century that are really driving this shift in focus that I talked about. On the one hand, it's sort of a big question about who's doing the funding of health research in the United States. If you go back to World War II, end of World War II, Cold War era, the federal government is heavily invested, for all sorts of national security reasons, in being a leader across the globe in health research. And so, '40s, '50s, the federal government, coming through places like the National Institutes of Health, is funding well over half of all health research that's being conducted in the United States. And then private industry, in contrast to those public dollars, is funding sort of the other sub-half. But in the '60s and the '70s, into the '80s, move all the way to the present, that shift goes dramatically in the direction of private industry funding the research and the public sector funding less of it. So in the world we live in today, private industry covers more like 70 to 80 percent of health research in the US, and our public dollars are only covering 20 to 30 percent.

[00:04:33] TABERY: So, what that means is we are turning our health R&D infrastructure over to private industry, which is focused primarily on raising money, on raising profit. And when you're in the business of making profit, you're going to be focused on domains where the studies you're conducting are likely to generate profit. And what we see is, in the realm of genomics generally, there are opportunities with pharmaceutical companies, medical device companies, diagnostic companies to make lots and lots of money with some new test or some new pharmacogenomic intervention or some new biomedical therapy. If you're looking to private industry, though, less of an incentive on that side of the equation to invest in environmental research because there's just fewer options for making money off that route, right? So the companies that are producing toxins and putting them out there into our air are not incentivized to do the research to figure out what sort of health problems are following from that.

And that's what you see sort of over and over again that whereas, on the biomedical side of private industry, there's a real incentive to try to invest in that research, on the social-environmental side, right, combating structural racism is not the kind of thing that companies are inclined to invest in, because it's not clear that they would know how to make money off of doing that. Making the air we breathe healthier again or water safer to drink is not the kind of thing that private companies are inclined to invest a lot of money in, because it's not clear that there's options for that. So I think that's one side of this equation. It's just that in the US, we are turning more and more of our health research over to private industry. And when you turn it over to private industry, they've

got a fundamental incentivization structure that's going to incline them in the direction of that sort of molecular genetic stuff and away from the social-environmental stuff.

[00:06:34] The other side of the equation, though, is even if you just focus on the public dollars, it also has focused and shifted over time to being more focused on molecular genetics. So, just think of the National Institutes of Health. If you go back to what that looked like in the beginning of the 20th century, it was much more focused on public health: on infectious diseases, on population health, on sort of identifying and preventing against epidemics, on developing vaccines, right? Essentially doing the research that's going to make the health of the whole US population better.

If you go and look at how the National Institutes of Health advertises itself to the world today, the claim is that it is the leading biomedical research organization in the world. And that shift from being about a National Institutes of Health to a national institute of biomedicine is encapsulated in what we've seen at the NIH over the last 50 or 60 years. It also—even though it's not working off of private dollars, it's working off of public dollars—has focused much more on molecular biology, cellular biology, genetics, sort of stuff going on at the cellular and subcellular level to tee up things like new diagnostics and new drugs and new opportunities for interventions on health. And that also then sort of pushes against focusing on environmental health things that cut across organ systems or social determinants of health, which are much harder to quantify and measure.

And so, there is this kind of weird tension where on the one hand, I would say there is more public and scientific attention to, and awareness of, the impact of social and environmental determinants of health than ever before. And yet, when you look at the research dollars that are available to do something about it, it is just swamped by the other dollars that are already out there that are focusing on things that have nothing to do with those contributions to health and wellness.

[00:08:40] HOFF: Hmm. That's very interesting. The ratio shift you're describing of previously public funding being a much larger percent, about half of research funding, is that ratio shift a result of less public investment or more private investment?

TABERY: It's a little bit of both. So, much of it in the early decades was a huge increase in private investment. What we've found, though, with investment on the public side of things, is it is becoming increasingly political. And what we find then is the NIH will often grow during certain administrations and contract under other administrations, right? So, in the US right now, we're at a moment of severe contraction within that public health, or in those public dollars for health research, whether it's the NIH or the CDC or the EPA. And so, that's a decrease on that side of it, where you still have the private sector investing in what it's doing.

HOFF: I'd like to get your insight into kind of another angle on that political pressure conversation.

TABERY: Sure.

[00:09:52] HOFF: One of the benefits of publicly funded research is that that profit motive is removed, certainly lessened.

TABERY: Right.

HOFF: Which allows funding to flow to ventures that might not be profitable, at least in the short term, obviously. Now, as we've seen in the past decade or so, increased scrutiny of how public resources are used, and really just hostility toward the idea of funding public goods at all, means that if a research venture is simply perceived as being unprofitable, it's at risk of having its funding cut.

TABERY: Yeah.

HOFF: So I guess the question is this: Is that political pressure a factor in the way that funding at public organizations has shifted, not only in how much is being allocated out of, for example, the federal budget, but also in which kinds of research are getting funding?

TABERY: Yeah, I think that's absolutely right. There's a couple things that are feeding into that, even on the public side of things. Ever since the 1980s into the 1990s, there's been a huge focus on public-private partnerships, where basically, what you've got is research, big, large-scale research projects at the NIH being conducted that are partly funded or resourced via, let's say, NIH resources, but also conducted with the financial investment and then support and influence of pharmaceutical companies, medical device companies. And this fusion of public and private was a real desire of the neoliberal political framework coming out of the Reagan years and then leading all the way up to the present that the way you harness the power of government is to make sure that there's also private industry investment that is appropriately incentivizing people to turn a profit. And so, even at these public funded institutions and agencies, what you've got are private dollar interests shaping what's going on there. And as you said, that's going to have an impact on what gets done.

I think the other thing that's also just worth paying attention to is this is something that cuts across political perspectives and inclinations. Democratic and Republican administrations alike have been enamored with the idea of cancer moonshots and genetic cures and breakthroughs. And there's something very powerful about the narrative of some new intervention, some new drug, some new gene therapy, some new immunotherapy that can save a baby who, without that therapy, would've died five years ago. And what you see are Democratic and Republican administrations alike making priorities of health research and health interventions that are likely to generate those narratives of cures, even if the people who actually benefit from them are few and far between. It is harder to get political leadership across the political spectrum to see the value of prevention. I think this is just a kind of fundamental challenge of public health research and implementation generally.

[00:13:03] People just take public health for granted. They sort of, they assume the water's going to be safe to drink, that the food's going to be okay to eat, that the air's

going to be safe to breathe, that the work they go and do is going to be a place where they can make a living, not get injured. And you typically don't see the impact of that work, the way which it makes populations healthier, until it's taken away and people start getting harmed by the absence. But it isn't as politically glossy and fancy to talk about just making the world a safer place. And I think that's another thing that's kind of worked against the social-environmental determinants of health research, because it doesn't naturally lend itself to those kinds of cure narratives, which are often very, very appealing to the public, to the media, and to politicians who want to put their names on initiatives.

[00:13:59] HOFF: Yeah, that's great. Thank you for laying that out so clearly. I want to shift and focus a little bit more closely on diagnostic research in particular. So, what do you see as merits and drawbacks of how diagnostic research, such as that done by the Undiagnosed Disease Network, seems to often draw prominently on genetic approaches to diagnostic problem solving?

TABERY: I think largely this is a question of what is it you're hoping to address, in terms of what health issue are you hoping to address? And is something like the Undiagnosed Disease Network and the way they go about investigating it the best way to do that? And I think what we want to say upfront—this speaks to the kind of merit side of what you were just saying—there are lots of conditions for which drawing on the genomic resources in the Undiagnosed Disease Network are a terrific resource for trying to do something about the problem that might be facing a family or a patient or a clinician. So, if you're thinking about, in particular, children just born and displaying some sort of complex assembly of conditions that don't naturally fall into the jaundice box or the premature birth box or something, right? There's sort of, there's something complicated going on here, and your average pediatrician or neonatologist hasn't seen this before.

It's, I would say, entirely reasonable to think, hey, why don't we do a whole genome sequence and see if there's something going on at the genomic level, right? Some de novo mutation or something that they may've inherited unexpectedly from parents that could explain this unusual manifestation that the physicians are seeing. And I think that's particularly reasonable in that case, because when you're thinking about what could've caused this problem that this patient, that this child is experiencing, they just haven't been in the world long enough to think that there's lots of opportunities for the environment to have wreaked havoc on them. Now, it might've been something in utero, right? It might've been something during delivery. Who knows, right? What they have had this whole time is their genome, and that has had an influence on how that baby's developed in the womb and is now developing outside the womb. And so, looking there to see if there's something lurking in the genome that could explain this unusual manifestation strikes me as really, really reasonable. So there's the merit side.

[00:16:31] When we shift to thinking about the drawbacks, I would say the danger lurks in pointing to isolated successes of some whole genome sequence providing some sort of insight into what a neonate is experiencing and thinking that that can be generalized in some more wider sense that's going to impact population-wide health. And let me sort of point to two cases where you see this playing out.

One example is there's a big push in the US and abroad to start doing whole genome sequencing just as a matter of course for every baby born in a hospital. And when you look at the sort of marketing of this push, it is always about catching these rare diseases that might otherwise be missed if you weren't doing whole genome sequencing of every baby born. And what we see there is the chances of you screening at a population level everybody for their whole genome having a tangible clinical impact on a baby's survival versus a lack of survival if you didn't have that genomic information is quite minimal. There's going to be few, few and far between cases where you're going to see, oh, we couldn't do what we could do with this baby because we didn't have their whole genome sequencing, but because we had it at birth and didn't wait until they started showing symptoms, let's say, two weeks later, all these clinical doors open that wouldn't have opened otherwise. But that's really the push for it. It's to say, look, we want to prevent these cases from arising.

In reality, what you're going to get are sort of 99.9 percent of babies born for whom this whole genome sequence provides no initial clinical value, but it will now become a permanent part of their health records. It will shape the way health care's perhaps presented to them, and not always for the good. It will be a valuable commodity for research. And what you'll find are straightforward efforts to try to monetize and gather that data because of the inherent value in it, not because it's actually doing anything of clinical value for the kids. And so, that's one real risk. Basically, there's this really isolated problem with a sort of precision intervention that can do something about it now being pitched as if it could be this population health intervention for which there's obvious ways in which it could be doing more harm than good.

[00:19:12] HOFF: Can you briefly expand on, you made a comment about that having your genome sequenced in your health record might shape the way that health care is offered or delivered to you in the future.

TABERY: Yeah.

HOFF: Can you expand on that briefly? Because I think there's a tendency for people to think like, oh, well, more information is better.

TABERY: Sure. Right, right, right. Well, I think there's a variety of things. I mean, now you might find—this is, again, I think it's the sort of the dream for the geneticists—that you are, that they're producing polygenic risk scores with that genetic information for all sorts of traits, right? So, if you've got my whole genome, you can spit out a polygenic risk score for me for heart disease, for cardiovascular disease, for a range of cancers, for any trait, you can do a PRS on it and spit out some risk score. For one, the clinical value and utility of that information remains severely limited. And two, it's not clear that you can do a whole lot with it, right? I mean, so, in many cases, if somebody says to you, "You're at a slightly increased risk for cardiovascular disease," the advice that we get from clinicians in response is, "Well, then you really should exercise, and you really should watch how much alcohol you take in and you should really eat a healthier diet." It's not that some new drug is available to you that wasn't available without that polygenic risk score information. And so, I think the danger here is because a polygenic

risk score can be produced for anything, and anybody can then get a risk score associated with it, suddenly everybody is a patient. Everybody is at risk of something. Everybody needs more medicine. Everybody needs more clinical care. And it's not obvious that that's the best way to actually make patients or populations healthier. So I think that's one of the problems with going this route.

[00:21:04] The other problem is there's just, you know, I think people assume, oh, if you got my genome, then what it's going to do is sort of spit out this fixed-in-time risk profile for me, that then, I'll know kind of who I am at the genomic level. But what you see about medical genetics over the decades is it is constantly updating what we know about different genetic variants and whether they increase or decrease risk and whether they're benign or actually pathological. And so, lots of what you're going to get out of something like that is just a trove of what geneticists call variants of unknown significance, which essentially, like, we have no idea what this means. And so, I don't think people are prepared for the possibility that what they're going to get back is either, one, a lot of just, "We don't know what this means," or two, information that at one point in time might say, "Hey, you're at risk of this. You should consider doing this as a result of that." And then a year later, they say, "Oh, we got some new information. It turns out you're no longer at risk of that." That's another case where I think it would just require a lot of education and a lot of humility in terms of how the importance of this information is actually conveyed to people if we think that what is in more information is inherently more useful routes to do something of value with that information.

HOFF: Yeah. A contributor to the Journal in the past have discussed that exact thing about is it beneficial to offer screening when you know that there are no resources there—

TABERY: Yeah.

HOFF: —to follow up with whatever results you happen to get?

TABERY: Yes. If all you can say is, "Congratulations. You're at risk." Yeah.

BOTH: [chuckle]

HOFF: Right, right. Exactly. And then is that actually better than not knowing in the first place?

TABERY: Yes. Yeah.

[00:22:51] HOFF: But to wrap up, I'd like to briefly discuss how priorities in genetic research have implications for health equity. One example cited in a recent article of yours illuminates that despite higher rates of sickle cell disease in the US, cystic fibrosis research receives more resources, it's the topic of more publications, it's the focus of more clinics, and it generates more interventions for patients with cystic fibrosis than for those with sickle cell disease. So, in your view, how might federal funding for personalized approaches to health be better apportioned to improve diagnostics and diagnostic research in ways that could promote equity?

TABERY: Well, I think the first thing that we would just want to say is if we are focused on molecular genetic approaches to personalized health, the impact on health equity right there is going to be minimal. And we just need to grant that and accept it. It's not to say that there isn't anything of value there, but we just want to be realistic about what's the actual scope of that impact going to be? So, what I mean by that is if you're thinking about what happens under the purview of personalized or precision medicine—this is typically pharmacogenetics. It's some sort of maybe targeted therapies for a particular cancer. Maybe it's a gene therapy for some particular rare disease, like you mentioned cystic fibrosis or sickle cell—the products of this are largely sort of expensive therapeutics that patients access once they're already in the health care system. And I think it's absolutely correct to say we want to make sure that as new therapeutics come along—maybe that's some new immunotherapy, maybe it's some new gene therapy, maybe it's some new pharmacogenomic treatment for diabetes—that that thing is accessible to anybody who needs it, right? So we don't want it to be the case that people, purely based on the color of their skin or the content of their genome, right, some people can access this immunotherapy and other people cannot. Or some people can use this particular drug and other people cannot. We want to make sure that the products of that research and of that investment are able to help anybody who needs it.

And so, I think if what we mean by this is, let's make sure that our personalized medicines, our precision medicines, are helpful for everybody who needs it, and we're conducting research in a way that makes sure that the population we're studying represents the population of the people who are out there and affected, and the products of that research are going to be subsidized and created in a way that things like financial barriers or geographic barriers aren't going to stand in the way of somebody accessing that thing that could make them healthier or save their lives, that's a good thing. I think that's sort of like not exacerbating inequity in the personalized and precision medicine sphere is a noble goal.

[00:25:49] But I think what sometimes happens, and this is where the problem emerges, is you point to a place where you're getting some uptake in, let's say, a personalized medicine that could do some good for a marginalized population and then say, "Aha! Look. Now we are treating the racial health disparities problem in society." And this is not the conclusion at all to derive from that previous thing that I was saying, right? The vast majority of disparities in society are not because of anything in our genomes. They're because we have put people in different parts of the environment, and we do things to that environment that makes it healthier or unhealthier to live in those spaces, right? So if you just systematically put people of certain sociodemographic makeups in neighborhoods where there are fewer parks, there's more traffic, there's more air pollution, the water's less healthy, there's a history of redlining, what you're going to find is, right, the people in that neighborhood are going to be sicker than the people on the other side of town, where there's lots of parks and hospitals nearby and lots of places to walk, and the air and the water and the grocery stores are all clean.

So, if you wanted to do something about health disparities in society at that population level, you really need to go out there and rethink what we're studying and how we're trying to engineer society to make it more equitable for the people who are living in it.

And there's nothing about a new gene therapy or some new immunotherapy that's going to get at the heart of that problem. And so, I think that's kind of how we want to understand it, that as we're developing these new molecular genetic interventions, we're doing so in a way that isn't going to exacerbate existing disparities, but also, just being sort of realistic about the fact that when we look at the existing disparities, by and large, those are driven not by things that happen after people come into the hospital, but by everything they experience out in life before they ever get to the hospital. [theme music returns]

[00:27:57] HOFF: Dr Tabery, thank you so much for your time on the podcast today.

TABERY: My pleasure. Thanks for the invitation. It was great to talk with you, Tim.

HOFF: That's all for this episode of *Ethics Talk*. Thanks to Dr Jim Tabery for being here. Music was by the Blue Dot Sessions. To read the full October 2025 issue on Diagnostic Research for free, visit our site, journalofethics.org. For our latest news and updates, follow us on Bluesky @amajournalofethics, and we'll be back next month with an episode on how Electronic Health Records Work or Don't in Street Medicine Contexts. Talk to you then.